END OF LIFE CARE: AFRICAN AMERICANS’ DISPROPORTIONATE USE OF HOSPICE

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The United States of America is a country composed of various ethnicities. This country is considered to be a multi-cultural society. There are various cultural traditions, values, norms and superstitious practices within each ethnic group. Attitudes toward end of life care are complex and vary differently across each ethnic group. This study explored factors that explained African Americans’ disproportionate use of hospice.

Access to hospice care was addressed, experience with hospice was explored, and recommendations were provided. This study conducted non-experimental research. The design of this exploratory study was quantitative in nature. A survey approach was utilized to collect data that was statistically analyzed. The important concept was African American disproportionate use of hospice. The variable willingness to use was employed to try to explain African Americans’ disproportionate use of hospice. The independent variables African Americans who mistrust formal healthcare providers and knowledge about hospice services were operationalized using multiple indicators. The independent variable experience with hospice services did not use a scale. The research findings supported all three study hypotheses.

This research results recommend that an important focus of the future be to counsel persons on the availability of hospice as an option for end-of-life care. Well-structured programs of training in cultural awareness and cultural competence throughout the ranks of the health care system must be instituted. Such an effort will pay dividends in reducing cultural mistrust and push closer to eliminating health disparities between minority groups and the rest of society.
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CHAPTER 1

INTRODUCTION

The United States of America is a country composed of various ethnicities. This country is considered to be a multi-cultural society. There are various cultural traditions values, norms and superstitious practices within each ethnic group. Attitudes toward end of life care are complex and vary differently across each ethnic group (Taxis, 2006). This study explored factors which may explain African Americans’ disproportionate use of hospice.

Problem Statement

Americans want to be sure that their wishes are honored at the end of life. Americans want to choose the types of services they can receive, pain control to be tailored to their wishes, and emotional support for their family (Taxis, 2006). Americans are willing to have an outside organization come into their homes and assist with care for a family member in the last stage of life. According to the National Hospice and Palliative Care Organization (NHPCO), hospice care addresses these major concerns of most Americans (NHPCO, 2006).

Hospice historically has served relatively few people of color, although some progress has been made (NHPCO, 2006). In 2006, 80.9 % of all hospice patients in the United States were white, and 8.2 % were African American, 4.9 % were Hispanic/Latino origin, 3.9 % were multiracial or other race, 1.8 % was Asian, Hawaiian or other Pacific Islander, and 0.3 % were American Indian or Alaskan Native. This data show disproportionate service for people of color by hospice. Furthermore, this data indicate that race and ethnicity may be associated with barriers to hospice care (NHPCO, 2006). This research will analyze why African Americans’ disproportionate use hospice.
Hospice care for African Americans has been limited. African Americans have not been offered hospice services suitable to their needs and backgrounds (Burrs, 1995). Increase understanding of the phenomena of caring for the terminally ill within the African American population may update efforts aimed at increasing access to hospice by African Americans. According to The National Hospice Organization (NHO), impeding access to hospice contributes to the lack of diversity in the hospice system (NHO, 1996). Lack of knowledge pertaining to hospice in African American communities also impedes access (Neubaur & Hamilton, 1990).

Literature Review

The delivery of hospice care follows a planned process. A patient and his or her family/primary caregiver are referred to a hospice (NHPCO, 2006). An initial assessment is completed by a nurse and social worker team. This team provides information to the patient and their families to aid them in understanding the service delivery system (NHPCO, 2006). This assessment team explains the necessary financial issues and options to the prospective patient and family. Besides the medical assessment, other procedures include reviewing insurance and financial assistance options; seeking and providing necessary medical equipment; connecting and linking patients and families with financial resources for living expenses, prescriptions, equipment, reimbursement, and providing information for discussing funeral arrangements (NHPCO, 2006). The patient is accepted if the patient chooses to receive and meet criteria for hospice care. The hospice, patient, caregiver and patient family develop a plan of care in which all parties become partners with the team in the total delivery of care to the patient (NHO, 1993).

Hospice care also includes bereavement services. The bereavement services that a hospice team offers after the patient’s death support the family members in their grieving
process, help them cope with their loss, and encourage them to become re-involved as fully functioning members of the community (Hayslip & Leon, 1992).

Hospice care can be traced back to pre-Christian Greece. During the 8th century, known as the Homeric times, a wanderer would be treated as a guest and offered food, clothing, shelter and a gift. The host providing these offerings was considered to be performing duties of hospitality (Edelstein, 1967). The hospice care concept has been recorded in 4th century Rome. A wealthy Roman lady named Fabiola, used her personal finances to care for the sick and terminally ill.

During the Crusades in 1095 to the end of the 17th century, weary travelers also found places of refuge in monasteries and nunneries. Often they were in ill health and many spent their last days cared for by monks, nuns and wealthy lay women (Edelstein, 1967). The name hospice was first applied to the care of dying patients by Mme Jeanne Garnier who founded the Dames de Claire in Lyon, France, in 1842 (Edelstein, 1967). In Ireland, Sister Mary Alikenhead of the Irish Sisters of Charity established Our Lady’s Hospice in 1846 to assist people transverse the last developmental stage of their life. In 1905, the sisters of charity expanded the concept of community based hospice care, opening St Joseph's Hospice in London, England (Edelstein, 1967).

In 1967, Dame Cicely Saunders started St Christopher’s Hospice after being inspired by a patient named David Tasma. Dame Saunders’ ideas have spread around the world, which gave her the reputation of being the founder of the modern hospice movement (Hayslip & Leon, 1992). St. Christopher’s Hospice has served as a model for service, research, and teaching in South London and the global community.
The hospice concept spread to the United States in 1974. Using Dr. Cicely Saunders as an inspiration, the Hospice of Connecticut was established in New Haven, Connecticut. The latest information according to the Centers for Medicare and Medicaid services (CMS) is that there are 3,071 Medicare certified hospice providers in the United States (CMS, 2008).

Most hospices in the United States use an interdisciplinary approach to hospice care. The interdisciplinary approach is a team of professionals who contribute or bring their individual knowledge and skills to the hospice interdisciplinary team (NHPCO, 2006). The interdisciplinary team is composed of the patient’s attending physician, the hospice medical director, registered nurses, social workers, home health aides, clergy or spiritual counselors, bereavement counselors, and trained volunteers. Other team members who play important roles in the patient’s care are physical therapists, art therapists, dietitians, music therapists, and pharmacists (NHPCO, 2006). Although certain of these professionals may perform specific tasks or responsibilities, there is overlap in the services because, using a holistic approach in hospice care, the patient’s and family’s welfare is the main concern of the interdisciplinary team (NHPCO, 2006).

Cancer patients made up the largest percentage of hospice admissions when the U.S. hospice community was established in the 1970s. In 2006, cancer diagnoses account for fewer than half of all hospice admissions. The top five chronic conditions served by hospice include heart disease, debility unspecified, dementia, lung disease and stroke or coma. (NHPCO, 2006).

Inpatient community residences are another arrangement in which a hospice can serve terminal ill patients and their families. Terminal patients who do no have a caregiver available may find a group home hospice a less expensive and more homelike alternative than an inpatient hospice or nursing home (NHPCO, 2006).
Large hospices have begun to open offices in rural areas where patients may have limited access to hospice services. These offices, referred to as satellites, are staffed by interdisciplinary teams which coordinate hospice care with its home hospice and use the home hospice’s specialized services or contracts for services from within the rural community it serves (NHPCO, 2006).

The National Hospice and Palliative Care Organization (NHPCO) estimates that 1.3 million patients received services from hospice in 2006, a 162% increase in 10 years. This estimate includes approximately 870,000 patients who died under hospice care, another 210,000 who were admitted to hospice in 2006, and approximately 220,000 patients who were discharged (NHPCO, 2006) (see figure 1).

![Figure 1. Patients who received Hospice Services in 2006 (NHPCO, 2006).](image)

Medicare stipulates four levels of care for reimbursement (CMS, 2008). They are routine home care, continuous home care, hospice inpatient care, and inpatient respite care. Each of the
categories of care has a base rate which includes a labor share and a non-labor share. Base rates are updated annually based on the hospital market basket index as shown in the chart below (CMS, 2008; see Figure 2). The Medicaid hospice benefit is patterned after Medicare and is available in most of the United States for eligible patients.

<table>
<thead>
<tr>
<th>Description</th>
<th>Rate</th>
<th>Wage Component Subject to Index</th>
<th>Non-Weighted Amount</th>
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<tbody>
<tr>
<td>Routine Home Care</td>
<td>$135.11</td>
<td>$92.83</td>
<td>$42.28</td>
</tr>
<tr>
<td>Continuous Home Care Full Rate =24 hours of care $32.86 hourly rate</td>
<td>$788.55</td>
<td>$541.81</td>
<td>$246.74</td>
</tr>
<tr>
<td>Inpatient Respite Care</td>
<td>$139.76</td>
<td>$75.65</td>
<td>$64.11</td>
</tr>
<tr>
<td>General Inpatient Care</td>
<td>$601.02</td>
<td>$384.71</td>
<td>$216.31</td>
</tr>
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*Figure 2. Medicare Reimbursement Rate Index (CMS, 2008).*

Every patient receiving hospice services will be on one of these four levels of care (NHPCO, 2006). A hospice patient can move from one level to another and back, depending on the services required fulfilling his or her needs. The need of the patient will determine their individual level of care. The four levels of care provided by hospices in the United States are:

Routine home care- A patient will be placed at this level of care if he or she resides at home (or a long-term care facility) and does not have symptoms which are out of control. These symptoms could include—but aren’t limited to—severe pain, continuous nausea and vomiting, bleeding, acute respiratory distress, and unbearable restlessness or agitation. The needs of the patient determine the number of visits from hospice staff members. These needs are established and outlined in a plan of care formed by the hospice team and the patient’s physician. The care
plan serves as a guideline to assist all those serving the patient with care. At this level of care the patient also has access to an on-call hospice nurse 24 hours a day (NHPCO, 2006).

Inpatient care- A hospice patient may require inpatient care when his or her symptoms have gotten out of hand and can no longer be managed at home. When these symptoms cannot be controlled on routine home care, then the patient requires extra attention until these symptoms subside. Hospices take aggressive actions to control the symptoms and make the patient comfortable. In order to do this, the patient may be temporarily placed in a hospice home or an acute care hospital. At this level of care, a moment-to-moment assessment of what’s happening and what needs to be done takes place. The hospice team and the patient’s physician work together to ensure the patient obtains and maintains a tolerable comfort level. Once this has been achieved, the patient will return home and back to routine home care (NHPCO, 2006).

Respite care- A patient may be moved to respite care when the caregiver needs a break. Many hospice patients live at home, with their family providing most of the care, sometimes around the clock. Caring for their loved one can be exhausting and very stressful. The family members and/or caregivers need time to themselves and it’s important that they take that time. Respite care allows a patient to be temporarily placed in a facility with 24-hour care so the family can rest. If the patient is willing and the family requests it, hospice must provide placement in a facility or a hospice home for the patient. The patient will be transferred to the facility, and according to Medicare regulations, can stay for up to five days before being transferred back home (NHPCO, 2006).

Continuous nursing care- A patient would receive continuous nursing care if he or she has symptoms that are out of control and chooses to stay at home. This is similar to inpatient care, except that the patient remains in his or her home instead of being placed in a facility. A
hospice nurse is required to provide continuous around-the-clock nursing care if the symptoms cannot be controlled while on routine home care (NHPCO, 2006).

When an individual choose a Medicare hospice provider for hospice care which is an elected benefit covered under Part A of Medicare, the individual signs a statement indicating that he or she elects the hospice benefit and waives all rights to Medicare payment for services for the terminal illness and related conditions. Medicare will continue to pay for covered benefits that are not related to the terminal illness (CMS, 2008).

Many private insurance companies have now instituted a hospice benefit. Insurance plans with these companies vary from coverage similar to and patterned after Medicare, to coverage that reimburses nursing visits or medical procedures but eliminates the psychosocial aspects of care (CMS, 2008).

Some patients are not eligible for Medicare or Medicaid, have insurance that does not include hospice benefits. Many of these patients have assets and can afford to pay all or part of the costs of hospice service. This method of payment is considered fee for service plan. Under this plan, patients are charged on an ability to pay sliding scale.

No one is rejected for hospice care for financial reasons. Patients who do not have insurance, are not eligible for Medicare or Medicaid, and have no assets are provided services without charge (CMS, 2008). These patients are considered indigent. Hospices generate funds from their communities, foundations, and other sources to maintain their ability to serve indigent and sliding scale clients (Cummings, 1985). Although reimbursement issues are complex and ever changing, they are crucial to providing access to services for patients and their families.

Quality is critical to the future of hospice. It is hospice’s unique reputation for doing more than the minimum that has been the foundation for its success (Balm, 2005).
Pain is often a part of the clinical problem the clinician must treat in the person with cancer. Since this symptom can lead to terrible suffering with a loss of quality of life, every hospice professional must be an expert in its relief (Foley, 2006). It is impossible for people who are dying and plagued by a multitude of symptoms, to be able to do the work necessary to live life until death. With good symptom control the individual is better able to manage the psychosocial issues they face during their illness, especially the goodbyes so necessary to achieve closure to both the patient and loved ones (Bruera, 2004).

Hospice programs provide a wide range of services based on the needs of the patient and family. It is important to determine the expectations of the patient and family prior to initiating hospice services. It is also necessary to continue to explore these expectations so that specific needs may be met by the appropriate resources (NHPCO, 2006). Questions and concerns should be identified and discussed as they arise. It is comforting for patients and families to know what to expect and how hospice workers can support them during this journey (Pickett, 2006).

Fifty-six percent of hospice patients are women versus 44% men (NHPCO, 2006). The majority of hospice patients in the United States are 65 years or older. This is expected to increase as the U. S. population ages (NHPCO, 2006).

The Medicare Hospice Benefit, enacted by Congress in 1982, is the dominant source of payment to hospice providers. Medicare will pay for hospice services if the patient has Medicare Part A or has been disabled for more than two years. Most private insurance companies will also pay for hospice care. There also exist charity care programs that do not seek federal reimbursement for patient care, but instead rely on community donations for support (CMS, 2006).
In the United States there are nonprofit and proprietary (for profit) hospice programs. Nonprofit are operated by a volunteer board of directors. Nonprofit hospices provide a service; pay taxes on purchases but not income. All donations to nonprofit hospices are tax deductible. Any profit is put back into the agency for program development (Kinzbrunner, 2002).

Proprietary (for profit) hospices are owner and/or investor managed. Monetary return is for owners/investors and profit is divided among them. These agencies pay taxes on both income and purchases. Donations to proprietary hospices are not tax deductible unless they have a foundation (Kinzbrunner, 2002). Differences in length of stay at non-profit and for-profit hospices are explained by selection of patients and early admission.

Several studies have shown that not only were African Americans more likely to choose more aggressive life-sustaining treatments, they were less likely to be enrolled in hospice at the end of life (Hopp & Duffy, 2000; McKinley, Garrett, Evans, & Danis, 1996). For instance, African Americans were found to have 40% lower hospice use than whites, and that hospice use was negatively associated with African Americans independent of income and access to healthcare (Greiner et al., 2003). Christakis and Escarce found that 92.4% of Medicare beneficiaries enrolled in hospice was white (Christakis and Escarce, 1996). Additionally, Welch, Teno, and Mor found that family members of African American decedents were two and a half times as likely as those of white decedents to report one or more problems with being informed about end-of-life medical care (Welch, Teno, and Mor 2005).

Although it is true that the African American culture is diverse, representing a collage of beliefs, traditions, and health practices, research data have suggested trends that may be useful in understanding the prevailing underutilization of hospice by African Americans. Studies have reported numerous barriers to African Americans using hospice services, including philosophical
differences; cultural mistrust; the influence of culture, family, and spirituality; and inadequate health insurance (Klessig, 1992, Neighbors & Jackson, 1987).

Hospice remains an underused resource for dying patients despite its rapid growth and acceptance (Friedman, Harwood, & Shields, 2002; Smucker, 2004). In particular, minority Americans are at greatest risk for underutilization of hospice care (Haber, 1999; Jackson, Schim, Seeley, Grunow, & Baker, 2000). Racial and ethnic minorities represent only 5%–7% of the hospice patient population (Reese, Ahern, Nair, O’Faire, & Warren, 1999). African Americans have 40% lower hospice use than whites (Virnig, Kind, McBean, & Fisher, 2000; Greiner, Perera, & Ahluwalia, 2003). Some researchers argue that these differences result from hard-to-measure socioeconomic factors, variations in insurance coverage, job or familial obligations, limited geographical access to hospice care, less at-home caregiver support, and lack of a primary care physician for hospice referral (Haber, 1999; Greiner, Perera, Ahluwalia, 2003; Gordon, 1995; Crawley, Payne, Bolden, Payne, Washington, & Williams, 2000). Others suggest that economic, educational, and access-to-care differentials between African Americans and whites are not the primary explanation (Greiner, Perera, Ahluwalia, 2003). There may be other important causes, such as differential care preferences, differences in knowledge to seek out or accept hospice care (Reese, Ahern, Nair, O’Faire, & Warren, 1999). Mistrust, also hypothesized to be a prominent barrier for African Americans may flourish most within a setting where the cultural/racial background of health care workers is not the same as the patient’s (Reese, Ahern, Nair, O’Faire, & Warren, 1999; Cort, 2004; Whaley, 2001). Given its philosophy, and the makeup of its workforce, hospice may be a foreboding place for African Americans (Cort, 2004).

A majority of all Americans would prefer to die at home but 62% of African Americans would prefer to die in the hospital (National Hospice Association, 1996; Field & Cassell, 1997;

There may also be a lack of agreement with the hospice philosophy among African Americans (Cort, 2004). African Americans see longevity as an intrinsic good, are reluctant to discuss advance directives, prefer curative care, and hesitate to welcome strangers from hospice into their homes (Klessig, 1992; Dupree, 2000; Ita, 1995-1996; Gordon & Rooney, 1984).

African Americans face peculiar barriers on the consideration of end-of-life and palliative care in general, and hospice care in particular. Within the African American community health care decisions are usually a family affair. Therefore, many African Americans first consult their family circle in making decisions about where to seek help, and show a general reluctance to go outside of their family circle for help with medical care-giving (Harper, 1999). As a corollary of this culture pattern they often hesitate to welcome strangers from hospice into their homes (Gordon, 1984). In addition, lack of knowledge about hospice services constitutes another barrier to hospice use for African Americans (Burrs, 1995; Harper, 1995).

The use of the emergency department rather than private physicians for health care can indirectly create another barrier for a sizable part of the African Americans community. Medicare regulations require that a physician certify terminality for entry into hospice programs (CMS, 2006). Many African Americans do not have a regular physician and are consequently without such certification and therefore unable to utilize hospice care (Neighbors & Jackson, 1987). Most striking is the lack of agreement with hospice philosophy among African Americans. Among other things, hospice philosophy stresses acceptance of death and palliative, rather than curative care (NHPCO, 2006). African Americans see longevity as an intrinsic good,
are often reluctant to discuss advance directives, and often prefer curative care as a means of avoiding the reality of certain death (Klessing, 1992; Dupree, 2000; Ita, 1995).

This perspective perhaps contributes to the reason that African Americans are the most reluctant of minority groups to agree to negotiate the end-of-life decisions concerning the withdrawing of life-prolonging therapy, tissue and organ donation, and palliative care in the hospice setting (Caralis, Davis, Wright, & Marcial, 1993; MacDonald, 1998; Reubens, 1996; Kinnon, 1999; Sabir, 1996; Griffin & Bratton, 1995). The discussion of barriers would do well to include what may look like a barrier from the vantage point of a health caregiver may be a protective strategy or a source of comfort and security when viewed from a different angle (Crawley, 2001).

Potential hospice patients are typically but not exclusively older persons. This cohort is often familiar with the Tuskegee study and feels that African Americans are still likely to be treated as guinea pigs by the health care system (Powers & Faden, 2003). In addition, they hold the belief that their race is devalued in the eyes of American society, and see this as the cause of episodes of neglectful and inhumane treatment in public health care facilities that provide care for poor people. These sentiments constitute a formidable barrier to the use of hospice care, and encourage this older generation to choose to care for themselves at home (Reese, Ahern, Nair, O’Faire, & Warren, 1999). Cultural mistrust within the context of the health care system in general, and hospice care in particular, is believed to be peculiar to African Americans (Gordon, 1995).

The perspective of mistrust seems to flourish most within a setting where the cultural/racial background of health care workers is not the same as the patients (Haber, 1999). Haber argues it is true that hospice facilities, for perhaps different reasons, have been unable to
attract minority volunteers and workers (Haber, 1999). This situation gives more fuel to the
cultural mistrust with which a patient may have entered the facility (Reese, Ahern, Nair, O’Faire,
& Warren, 1999).

The health care system is further caught in what may be described as the proverbial “rock
and a hard place,” when it comes to cultural mistrust. Haber describes this dilemma thus:
“Cultural insensitivity and mistrust are engendered by a health care system that tends to be
complex, busy, impersonal, and often brusque . . . hospice care which is not impersonal or
brusque, may be viewed by minority families as intrusive, especially if they believe that
unfamiliar caregivers will try to take over and change things” (Haber, 1999). Even in cases
where hospice workers may enter the home, their presence may not be welcomed into the
intimacy of the racial/ethnic family, and viewed with mistrust, especially when they are seen as
mainstream health care workers with ties to the mainstream health care system (Gordon, 1984).
The dilemma for hospice is that hospice, being what it is in terms of its philosophy, and the
makeup of its workforce, is a foreboding place for African Americans.

Theory

The application of cognitive-behavior theory attempts to help persons with a diagnosis of
a terminal disease change their maladaptive thinking habits to relieve emotional disturbances
such as depression, anger, and anxiety, and to more generally facilitate everyday adjustment
(Adams, 2006).

The United States of America is a country composed of various ethnicities. This country
is considered to be a multi-cultural society. There are various cultural traditions values, norms
and superstitious practices within each ethnic group. Attitudes toward end of life care are
complex and vary differently across each ethnic group (Taxis, 2006).
Hospice remains an underused resource for dying patients despite its rapid growth and acceptance (Friedman, Harwood, & Shields, 2002; Smucker, 2004). In particular, minority Americans are at greatest risk for underutilization of hospice care (Haber, 1999; Jackson, Schim, Seeley, Grunow, & Baker, 2000). Racial and ethnic minorities represent only 5%–7% of the hospice patient population (Reese, Ahern, Nair, O’Faire, & Warren, 1999). Blacks have 40% lower hospice use than whites (Virnig, Kind, McBean, & Fisher, 2000; Greiner, Perera, & Ahluwalia, 2003).

The National Hospice and Palliative Care Organization (NHPCO) estimated that 1.3 million patients who had a terminal diagnosis, received services from hospice in 2006 (NHPCO, 2006). Many of these are diagnosed before their functioning had been compromised, meaning they are capable of participating in decision-making, and life in as normal a manner as possible. Many of those diagnosed with a terminal disease experienced a variety of reactions to the diagnosis and the changes they are experiencing. These include frustration, difficulty with self-expression, and anxiety, memory loss issues as well as fear of being a burden (Adams, 2006).

A diagnosis of a terminal illness is a disturbing time, but it can also provide opportunities to make positive adjustments to the disease. It means that the person with the diagnosis can be involved in future planning. Future planning can be undertaken regarding future disability and death, and allows an opportunity to look back and assess meaning in one’s life. A terminal diagnosis usually brings with it a reordering of priorities (Adams, 2006).

When a terminal diagnosis is made, it drastically changes the life course. Jobs end, painful decisions are made about the future, including anticipating incapacity by both loved ones and the recently diagnosed. One of the issues that develop is the idea of helplessness, loss of
control of one’s life and the immediate loss of meaning in such a painful and vicious way (Adams, 2006).

Hospice programs provide a wide range of services based on the needs of the patient and family. It is important to determine the expectations of the patient and family prior to initiating hospice services. It is also necessary to continue to explore these expectations so that specific needs may be met by the appropriate resources (NHPCO, 2006). Questions and concerns should be identified and discussed as they arise. It is comforting for patients and families to know what to expect and how hospice workers can support them during this journey (Pickett, 2006).

There are many cognitive competencies such as level of mastery of the basic pragmatics of life, awareness that there are limits to one’s knowledge, awareness of the existence of ill-structure problems, and a competency for formulating appropriate and feasible judgments in the face of uncertainty (Marchand, 2003). Cognitive and behavioral interventions have been used effectively to restructure distorted cognitions. Cognitive and behavioral interventions have also been used to help in the development of coping skills for those with a terminal diagnosis. Cognitive and behavioral interventions have provided relief from fear, anxiety and depression (Marchand, 2003).

A person with a terminal illness can learn to cope with the diagnosis and prognosis by developing a functionally healthy acceptance of the situation and adaptive behavior (Adams, 2006). A person diagnosed with a terminal disease faces the potential of a devastating future and a present that is negatively impacted as well. Careers are given up due to the diagnosis, driving is either eliminated or drastically restricted, plans for retirement are scrapped either because of the financial impact of the disease or the reality that future cognitive changes may make some things impossible (Adams, 2006).
Cognitive theory is useful in understanding how negative thoughts develop and how appropriate intervention techniques were developed for coping when dealing with major life stressors (Beck, Rush, Shaw and Emery, 1979). Cognitive theory refers to methods of intervention that considers thoughts, self-verbalizations, decisions, accessible beliefs, values, and attributions. Cognitive theory seeks to work with these structures by understanding the meaning given, and intervening to provide positive functioning and relief from negative thoughts (Granvold, 1995). Cognitive techniques can assist with adjustment to the terminal diagnosis, the development of appropriate goals and social support networks.

Cognitive approaches recognize a reciprocal determinism model (Beck & Emery, 1985). Cognitions, behavior, and personal factors such as emotion, motivation, physiology and physical factors interact with social-environmental factors. Since cognitions are considered to be intrinsic in the dysfunction, cognitive therapy seeks to modify the cognitive factors that are operational in the client’s distress. Cognitive behavioral therapy looks at what the maladaptive behavioral response is and how to change it. The therapist teaches the client to monitor distorted, automatic thoughts, and then to challenge them (Beck & Emery, 1985).

A diagnosis of a terminal illness is a disturbing time, but it can also provide opportunities to make positive adjustments to the disease. It means that the person with the diagnosis can be involved in future planning. Future planning can be undertaken regarding future disability and death, and allows an opportunity to look back and assess meaning in one’s life. A terminal diagnosis usually brings with it a reordering of priorities (Adams, 2006).

When a terminal diagnosis is made, it drastically changes the life course. Jobs end, painful decisions are made about the future, including anticipating incapacity by both loved ones and the recently diagnosed. One of the issues that develop is the idea of helplessness, loss of
control of one’s life and the immediate loss of meaning in such a painful and vicious way (Adams, 2006).

Cognitive theory is useful in understanding how negative thoughts develop and how appropriate intervention techniques were developed for coping when dealing with major life stressors (Beck, Rush, Shaw and Emery, 1979). Access to hospice care was addressed, and recommendations were provided.

Hospice in the United States is an alternative to traditional methods of caring for the terminally ill (NHPCO, 2006). In addition to providing skilled medical services to the patient in the home or nursing facility, hospice also seeks to holistically meet the social, emotional, and spiritual needs of the patient, caregiver and family (NHPCO, 2006).

Hypotheses

The purpose of this study was to explore factors related to African Americans disproportionate use of hospice. The hypotheses were:

- African Americans who mistrust formal healthcare providers are less likely to use hospice. Hospice care for African Americans has been limited. African Americans have not been offered hospice services suitable to their needs and backgrounds (Burrs, 1995). Mistrust, also hypothesized to be a prominent barrier for blacks, may flourish most within a setting where the cultural/racial background of health care workers is not the same as the patient’s (Reese, Ahern, Nair, O’Faire, & Warren, 1999; Cort, 2004; Whaley, 2001). Given its philosophy, and the makeup of its workforce, hospice may be a foreboding place for blacks (Cort, 2004). Cognitive theory is useful in understanding how negative thoughts develop and how appropriate intervention techniques were developed for
coping when dealing with major life stressors (Beck, Rush, Shaw and Emery, 1979).

- African Americans with more knowledge about hospice are more willing to use hospice services. Lack of knowledge pertaining to hospice in African American communities impedes access (Neubaur & Hamilton, 1990). Increased understanding of the phenomena of caring for the terminally ill within the African American population may update efforts aim at increasing access to hospice by African Americans.

- African Americans with more experience with hospice are more likely to use hospice services. There are many cognitive competencies such as level of mastery of the basic pragmatics of life, awareness that there are limits to one’s knowledge, awareness of the existence of ill-structure problems, and a competency for formulating appropriate and feasible judgments in the face of uncertainty (Marchand, 2003). Cognitive and behavioral interventions have been used effectively to restructure distorted cognitions. Cognitive and behavioral interventions have also been used to help in the development of coping skills for those with a terminal diagnosis. Cognitive and behavioral interventions have provided relief from fear, anxiety and depression (Marchand, 2003).
CHAPTER 2

METHODS

This study was exploratory research and quantitative in nature. A survey approach was utilized to collect data that was statistically analyzed. The majority of hospice patients are the age 35 years upwards (NHPCO, 2006) (see figure 3). The target population was African Americans age 35 years upwards. The sample size was 100 African Americans from Carter County, Oklahoma.

![Figure 3. Percentage of patients served by age group in 2006 (NHPCO, 2006).](image)

The target areas were African American communities and places within African American communities that African Americans frequent such as barber shops, beauty parlors, physical fitness centers, African American communities all purpose centers, and African American community churches. This allowed for cultural sensitivity and facilitate for the highest rate of participation possible. This also facilitated the most effective data collection survey instrument method that could be collected in the group setting.
Protection of Human Subjects

This proposed study was presented to the Institutional Review Board (IRB) of the University of North Texas. The study results may be published but names and identities are not revealed. Participants were told that they were being asked to participate in a survey on attitudes toward hospice care. Participants were informed that this research was part of a doctoral student’s dissertation. Participants were informed that participation was voluntary. Participants were informed that there were no penalties for participation, non-participation, or withdrawing from participation in the research study. Participants were advised of the benefits and potential risks involved. Participants were informed that psychological discomfort may be experienced related to participating in this study. Participants were encouraged to withdraw without fear of penalty from this research study if these psychological experiences occur. Participants were informed they had the opportunity to discuss any feelings of discomfort following the completion of the survey. Participants were informed that participation in this research study may assist in understanding why African Americans disproportionately use hospice at the end of life. Participants were informed that their participation may also improved access to hospice care by African Americans at the end of life. The study participants were offered the results of the research study when completed.

I used the following schedule with the approval of the places within African American communities that African Americans frequent. I visited the barber shops and beauty parlors on Thursdays, Fridays and Saturdays between 10 a.m. and 8 p.m. These are the days and hours when the barber shops and beauty parlors are most busy.
I visited the physical fitness centers that African Americans frequent doing their heaviest hours of operation. These hours are usually 6 p.m. through 9 p.m. Mondays through Fridays, and Saturdays 10 a.m. through 2 p.m.

Sample Selection

The target cites and towns in Carter County were Ardmore, Springer, and Marietta, Oklahoma. The target communities areas were African American and places within African American communities that African Americans frequent such as barber shops, beauty parlors, physical fitness centers, African American communities all purpose centers, and African American communities churches. I received permission from the owners, operators, directors, and managers of each venue and the African American community churches’ ministers to survey all African American clients, customers, members, and visitors including all African American owners, operators, directors, managers, staff and the African American community churches’ ministers who are African American. Participants were told that they were being asked to participate in a survey on African Americans disproportionate use of hospice. That this research is part of a doctoral student’s dissertation research.

I received permission from the owners and operators of the barber shops and beauty parlors which African Americans frequent to survey all patrons and visitors that were African American (including the staff, owners and operators of the barber shops and beauty parlors) present at the barber shops and beauty parlors doing the hours of operation. These hours are usually 7 a.m. through 9 p.m. Tuesdays through Saturdays with Thursdays, Fridays, and Saturdays the days when the barber shops and beauty parlors are most busy with patrons and visitors. I received information from the owners and operators as to the most appropriate times and days to present the survey instrument.
I received permission from the directors and managers of the physical fitness centers which African Americans frequent to survey all clients, customers, participants, and visitors that are African American (including the directors, managers and the staff) present at the physical fitness centers doing the hours of operation. These hours are usually 5 a.m. through 9 p.m. Mondays through Saturdays. I received information from the directors and managers as to the most appropriate times and days to present the survey instrument.

I received permission from the directors and managers of the community all purpose centers located in the African American communities to survey all clients, customers, participants, and visitors that are African American (including the directors, managers and the staff) present at the community centers doing the hours of operation. These hours are usually 8 a.m. through 9 p.m. Mondays through Fridays and 9 a.m. through 8 p.m. on Saturdays. I received information from the directors and managers as to the most appropriate times and days to present the survey instrument.

I received permission from the African American community churches ministers to survey all members and visitors that are African American (including the ministers and the church staff) present doing the Sunday worship service. This is when most if not all of the churches members and staff are present. The Sunday worship hours varies between 8 a.m. and 10 a.m. until 1 p.m. I received information from the African American community churches ministers as to the most appropriate times and days to present the survey instrument.

I visited the community all purpose centers that African Americans frequent doing their hours of operation between 9 a.m. and 8 p.m. Mondays through Fridays and between 10 a.m. and 6 p.m. on Saturdays. I visited between the hours of 10 a.m. and 2 p.m. Mondays through Fridays to survey the elderly African Americans. These were the hours in which the elderly
African Americans frequent the all purpose community centers. I visited the African American community churches doing the Sunday worship service. I visited between 8 a.m. and 1 p.m. This is when most if not all of the churches members are present.

Survey Procedures

I provided the survey instrument to all who agreed to participate who fit the selection criteria on day of my visit to each of the venues. I explained and provided instructions on how to complete the survey instrument. I provided each participant with a survey instrument with instructions and a sharpened lead pencil with an eraser top to complete the survey instrument. Participants were informed that participation was voluntary. Participants were informed that there were no penalties for participation, non-participation, or withdrawing from participation in the research study. Participants were advised of the benefits and potential risks involved. Participants were informed that psychological discomfort may be experienced related to participating in this study. Participants were encouraged to withdraw without fear of penalty from this research study if these psychological experiences occur. Participants were informed they had the opportunity to discuss any feelings of discomfort following the completion of the survey. Participants were informed that participation in this research study will assist in understanding why African Americans disproportionately use hospice at the end of life. Participants were informed that their participation may also improved access to hospice care by African Americans at the end of life. The study participants were offered the results of the research study when completed.

The survey consisted of questions being answered using a five (5) point Likert scale. Responses varied from strongly agree to strongly disagree. Several questions were, “mark with
an “X” and fill in the blanks. A letter of inform consent was included and I provided instructions for completing the survey and describing the study. The surveys were conducted anonymously.

To ensure clarity and cultural sensitivity the survey was reviewed by this study’s research panel. This research panel consisted of a medical doctor, an educator, a community activist, and a police officer. This study’s research panel consisted of African American males and females. The research question guiding this study was: “Why do African Americans disproportionately use hospice?”

This study:

1. Built upon previous studies related to access to hospice care by African Americans.
2. Explored why African Americans underutilize hospice.
3. Explored Africans Americans concept of hospice.
4. Proposed potential remedies to resolve disparities in African Americans accessing hospice care.

Conceptual Definitions of Key Concepts

The term hospice is a derivative of the word hospitality which comes from the Latin word *hospes* which means to host a guest or stranger. Hospice is a type of care for patients who are close to dying from an illness. Hospice is not a place but a concept of care that is recognized as the model of quality, compassionate health care delivery for people facing life-limiting illness (Barker, 1995). Factors were defined as impediments and obstructions in accessing hospice. Disproportionate was defined as underutilization of hospice. Perception was defined as beliefs about the appropriateness of hospice. Access was defined as admission and the right to use hospice. Negative and positive experiences referred to previous encounters with hospice.
Measurement Method

Survey methods are especially useful when describing the characteristics of a larger population (Babbie, 2007). Carefully selected probability sample in combination with standardized questionnaire increases the external validity of the study (Babbie, 2007). This study utilized a non-probability convenience sample method. While non-probability samples reduce the generalizability of this research study, the purpose of utilizing a non-probability convenience sample was to identify African Americans that may have limited exposure to hospice. Even though the possibility of selection bias may limit generalizability to all African Americans, the purpose of this study and the reality of African Americans underutilization of hospice necessitated that this study include a non-probability convenience sample. This assisted in understanding African Americans perceptions and actual experiences with hospice.

Survey research tends to be strong on reliability and weak on validity (Babbie, 2007). This research utilized variations of instances of willingness to use hospice. Participants were provided with standardized questions. This method provided consistency, thereby increasing reliability.

A definition of hospice care was included for survey respondents. Content validity was established after consideration of concepts from previous literature. The definition of hospice, for instance, was taken from the National Hospice & Palliative Organization Standards of a Hospice Program of Care. The survey was measured by determining how effective perceptions of hospice were in predicting the likelihood of accessing hospice. Face validity was judged by this study’s research panel.

Reliability refers to a measure’s ability to yield consistent results each time it is applied. Reliability has to do with the amount of random error in a measurement (Babbie, 2007). The
possibility of selection bias may limit generalizability to all African Americans; the purpose of this study is to realize why African Americans underutilize hospice. The more reliable a measure is the less random error in it. If an instrument/measure, in general, was valid, it is most likely reliable (Babbie, 2007). Testing the reliability of an instrument is a little more straightforward than validity. There are different ways to evaluate reliability. Reliability is population-specific so it cannot be generalized across populations (Babbie, 2007). The population in this research was African Americans.

Survey data collection made it possible to analyze multiple variables simultaneously. Study indicators represented the nominal and ordinal levels of measurement.

Dependent Variable

The important concept was African American disproportionate use of hospice. The variable willingness to use was employed to try to explain African American disproportionate use of hospice. To operationalize this concept, two different items were included. One item states “If I had a terminal illness, I would likely use hospice services,” (see Survey Question 13). Another item states, “If you found out that you had a terminally illness and had six months or less to live, do you think you would use hospice services,” (see Survey Question 17)? That item only allows for closed-ended answers of “yes” or “no” (see Survey Question 17). Because the former item (see Survey Question 13) allows for a wider variety of responses from strongly agree to strongly disagree, the survey participants were allowed to give more of an intensity of response. Therefore this item is used as the dependent variable.

Independent Variables

The independent variables took into consideration previous negative experiences, the participants’ awareness of hospice, as well as their perceptions by asking the participants about
their perceptions concerning hospice. The independent variables African Americans who mistrust formal healthcare providers and knowledge about hospice services were operationalized using multiple indicators. The independent variable experience with hospice services did not use a scale. Coefficient Alpha was used to check for scaling properties for mistrust of formal healthcare providers and knowledge about hospice.

Independent variables:

1. Knowledge of hospice
2. Relative/friend experience with hospice
3. Mistrust of formal healthcare providers

Table 1

*Cronbach Coefficient Alpha for MISTRUST Factors*

<table>
<thead>
<tr>
<th>Raw Alpha</th>
<th>Standardized Alpha</th>
<th>Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.656697</td>
<td>0.688401</td>
<td>0.524856</td>
</tr>
</tbody>
</table>

As indicated in Table 1, there is a strong relationship between comfort with being admitted into a hospital and comfort using doctors and clinics, resulting in a raw coefficient alpha of 0.66, standardized 0.69. This is an adequate alpha to allow for the creation of a scale. The difference between the raw and standardized alpha is small, allowing for the creation of a raw scale, by simply adding the two variables together and rebasing to 1 as the lowest value (see Table 1).

Table 2

*Cronbach Coefficient Alpha for Knowledge Factors*

<table>
<thead>
<tr>
<th>Raw Alpha</th>
<th>Standardized Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.598330</td>
<td>0.608468</td>
</tr>
</tbody>
</table>
As indicated in Table 2, there are moderate relationships among knowledge of hospice as a type of care, concept of care, model of health care, and provider of healthcare services. The raw coefficient alpha is 0.60, standardized 0.61, allowing creation of a scale for knowledge, the minor difference between raw and standardized alphas allowing for an additive scale. Given the Likert scoring, to measure knowledge, the Likert scores must be reversed before being added; and the scale is rebased to 1 as the lowest scale score (see Table 2).

The independent variables African Americans who mistrust formal healthcare providers, experience with hospice, and knowledge about hospice cause the dependent variable African Americans willingness to use hospice.

Control Variables

This study controlled for the demographic factors of age, gender, level of education and household composition. Additional variables were considered as controls, but because of the sample size, it was judged that only four control variables (plus the three independent variables) could be used in multivariate analysis. These variables were operationalized by asking the participants to select the most relevant item from a selection of choices. This study also controlled for negative experiences and awareness of and accessibility to hospice. Negative experience was operationalized by asking participants if they or anybody close to them have ever experienced hospice care and how helpful and suitable was the care. The variables perception and awareness of hospice were measured by asking participants to identify how aware they were of the purpose of hospice.

Age was important because older persons tend to use hospice the more. Gender was important because females tend to use hospice more than males. Education was examined to determine the likelihood of more education influencing hospice use. Education was measured in
five categories (see Table 16 below), but only one distinction on education (college graduate versus not) was used, that showed the strongest prediction of the outcome variable.

Household composition (living alone or not) was selected as a control variable to explore whether a person living alone would be more willing to use hospice, based on the reasoning that those with other persons in their households would be more likely to have social supports that would take care of them in their final weeks of life.

The four control variables chosen were:

1. Age
2. Gender
3. Education
4. Household composition
CHAPTER 3

FINDINGS

The important concept was African American disproportionate use of hospice. The variable willingness to use was employed to try to explain African American disproportionate use of hospice. The independent variables African Americans who mistrust formal healthcare providers and knowledge about hospice services were operationalized using multiple indicators. The independent variable experience with hospice services did not use a scale. This study controlled for several demographic factors to establish causality, took into consideration previous negative experiences, the participants awareness of hospice, as well as compared how actual experiences with hospice affected their perceptions by asking the participants about their perceptions concerning hospice. As the design controlled for several factors, this survey made it possible to analyze multiple variables simultaneously. Study indicators represented the nominal and ordinal levels of measurement. This study controlled for the demographic factors of age, gender, level of education and household composition.

Descriptive Statistics

Descriptive data statistics used frequency distributions from these variables and means where appropriate. A variety of controls were entered. The questionnaire was designed to obtain information concerning African Americans experience with hospice, access to hospice, knowledge of hospice, and the demographic characteristics of the sample population. The complete questionnaire is included as appendix A.

One item states, “If I had a terminal illness, I would likely use hospice services,” (see Survey Question 13). Over half of the respondents (53%) indicated they strongly agreed or
agreed with this statement; about one-fifth (22%) of respondents were uncertain, disagreed, or strongly disagreed with this statement (see Table 3).

Table 3
Likelihood of Using Hospice Services

<table>
<thead>
<tr>
<th>Responses</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>21</td>
<td>21%</td>
<td>21</td>
<td>21%</td>
</tr>
<tr>
<td>Agree</td>
<td>32</td>
<td>32%</td>
<td>33</td>
<td>53%</td>
</tr>
<tr>
<td>Uncertain</td>
<td>19</td>
<td>19%</td>
<td>20</td>
<td>72%</td>
</tr>
<tr>
<td>Disagree</td>
<td>2</td>
<td>2%</td>
<td>2</td>
<td>74%</td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>1</td>
<td>1%</td>
<td>1</td>
<td>75%*</td>
</tr>
</tbody>
</table>

*NOTE: 25 observations were deleted due to missing values for the response or explanatory variables.

Another item states, “If you found out that you had a terminal illness and had six months or less to live, do you think you would use hospice services,” (see Survey Question 17)? Which only allow for close end answers of yes or no (see Survey Question 17)? Because the former item allows for a wider variety of responses from *strongly agree* to *strongly disagree*, the survey participants were allowed to give more of an intensity of response (see Survey Question 13). Therefore, this item is used as the dependent variable. Again, over half of the respondents (54%) *strongly agreed* or *agreed* with the statement (see Table 4).
Table 4

Likelihood of Use of Hospice with Terminal Illness

<table>
<thead>
<tr>
<th>Responses</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>21</td>
<td>21%</td>
<td>21</td>
<td>21%</td>
</tr>
<tr>
<td>Agree</td>
<td>33</td>
<td>43%</td>
<td>33</td>
<td>54%</td>
</tr>
<tr>
<td>Uncertain</td>
<td>20</td>
<td>26%</td>
<td>20</td>
<td>74%</td>
</tr>
<tr>
<td>Disagree</td>
<td>2</td>
<td>2%</td>
<td>2</td>
<td>76%</td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>1</td>
<td>1%</td>
<td>1</td>
<td>77%*</td>
</tr>
</tbody>
</table>

Probabilities modeled are cumulated over the lower Ordered Values.

*NOTE: 23 observations were deleted due to missing values for the response or explanatory variables.

Within the African American community health care decisions are usually a family affair. Therefore, many African Americans first consult their family circle in making decisions about where to seek help, and show a general reluctance to go outside of their family circle for help with medical care-giving (Harper, 1999).

Question 7 on the survey the likelihood of use of hospice variable, states, “My family would care for me at home if I had a terminal illness”. On the family care at home variable eleven respondents strongly agreed, twenty -two respondents agreed, fifty-three respondents were uncertain, and twelve respondents disagreed and two respondents strongly disagreed (see Survey Question 7). This variable had one hundred percent response (see Table 5). This variable did not predict anything. It did not have sufficient strength to be used as a control variable.
Table 5

*Family Care at Home*

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>11</td>
<td>11%</td>
<td>11</td>
<td>11%</td>
</tr>
<tr>
<td>Agree</td>
<td>22</td>
<td>22%</td>
<td>33</td>
<td>33%</td>
</tr>
<tr>
<td>Uncertain</td>
<td>53</td>
<td>53%</td>
<td>86</td>
<td>86%</td>
</tr>
<tr>
<td>Disagree</td>
<td>12</td>
<td>12%</td>
<td>98</td>
<td>98%</td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>2</td>
<td>2%</td>
<td>100</td>
<td>100%</td>
</tr>
</tbody>
</table>

Missing values= 0

The use of hospice requires that both the patient and the family acknowledge impending death, a concept that often runs counter to African Americans spiritual beliefs. Most African Americans believe that God is benevolent and has miraculous powers and only God can make life and death decisions (Taxis, 2006). Some African Americans would rather pray for a miracle than accept terminality, which may be viewed as a breach of faith. A reluctance to plan for death echoes a belief that death is accepted as a welcome friend and will come when it is God’s will (Taxis, 2006).

Question 10 on the survey, the prayer variable, states, “Prayer is important when I am dying”. On the prayer variable sixty nine respondents strongly agree, twenty eight respondents agree, two respondents were uncertain, and one respondent strongly disagreed (see Survey Question 10).
Prayer has ninety-seven respondents who either strongly agreed or agreed that prayer was important when a person was dying verse the one who disagreed or the two who were uncertain (see Table 6). Although this variable had one hundred percent response, it did not have sufficient variation to be used as a control variable.

Question 14 on the survey, the service provider preference variable, states, “If I had a choice of a healthcare provider, I would prefer to receive services from an African American”. The service provider preference variable had fourteen respondents strongly agree, thirty-three respondents agree, thirty-five respondents were uncertain, thirteen respondents disagree and one respondent strongly disagreed (see Survey Question 14). This variable had four missing values (see Table 7). This variable described the population; however it did not have enough predictive power to be used as a control variable.

### Table 6

**Importance of prayer**

<table>
<thead>
<tr>
<th>Response</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>69</td>
<td>69%</td>
<td>69</td>
<td>69%</td>
</tr>
<tr>
<td>Agree</td>
<td>28</td>
<td>28%</td>
<td>97</td>
<td>97%</td>
</tr>
<tr>
<td>Uncertain</td>
<td>2</td>
<td>2%</td>
<td>99</td>
<td>99%</td>
</tr>
<tr>
<td>Disagree/Strongly Disagree</td>
<td>1</td>
<td>1%</td>
<td>100</td>
<td>100%</td>
</tr>
</tbody>
</table>

Missing values=0
Table 7

*Service Provider Preference*

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>14</td>
<td>14.58%</td>
<td>14</td>
<td>14.58%</td>
</tr>
<tr>
<td>Agree</td>
<td>33</td>
<td>34.38%</td>
<td>47</td>
<td>48.96%</td>
</tr>
<tr>
<td>Uncertain</td>
<td>35</td>
<td>36.46%</td>
<td>82</td>
<td>85.42%</td>
</tr>
<tr>
<td>Disagree</td>
<td>13</td>
<td>13.54%</td>
<td>95</td>
<td>98.96%</td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>1</td>
<td>1.04%</td>
<td>96</td>
<td>100%</td>
</tr>
</tbody>
</table>

*NOTE: 4 observations were deleted due to missing values for the response or explanatory variables.*

Religion was a possible predictor of hospice use. The religious preference variable had three respondents identified themselves as Catholic, seventy-nine respondents identified themselves as Baptists, four respondents identified themselves as Methodists, nine respondents identified themselves as Pentecostal, two respondents identified themselves as Jehovah Witnesses and one respondent identified as other (see Survey Question 16). Over 80% of the respondents identified themselves as Baptists (see Table 8). This variable had two missing values. This variable described the population’s religious preference, which was overwhelmingly Baptist. Unsurprisingly, given the lack of variation, religious preference did not have enough predictive power to be used as a control variable in the multivariate analysis.

Table 8

*Religious Preference*

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catholic</td>
<td>3</td>
<td>3.06%</td>
<td>3</td>
<td>3.06%</td>
</tr>
<tr>
<td>Baptist</td>
<td>79</td>
<td>80.61%</td>
<td>82</td>
<td>83.67%</td>
</tr>
<tr>
<td>Methodist</td>
<td>4</td>
<td>4.08%</td>
<td>86</td>
<td>87.76%</td>
</tr>
<tr>
<td>Pentecostal</td>
<td>9</td>
<td>9.18%</td>
<td>95</td>
<td>96.94%</td>
</tr>
</tbody>
</table>
Those who would use hospice does increase with age (see survey question # 22). Those who say they would use hospice goes from 17% to 45% to 65% to 82% to 98% (see Table 9). Preliminary analysis showed that distinguishing those aged 55 and over from younger respondents showed the strongest prediction of the dependent variables, so that measure was employed as a control in the multivariate analysis (although it does not show as significant in that analysis). There were six missing values on age.

Table 9

<table>
<thead>
<tr>
<th>Age of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
</tr>
<tr>
<td>--------------------</td>
</tr>
<tr>
<td>Up to 18</td>
</tr>
<tr>
<td>19–34</td>
</tr>
<tr>
<td>35-54</td>
</tr>
<tr>
<td>55-64</td>
</tr>
<tr>
<td>65-74</td>
</tr>
<tr>
<td>75-84</td>
</tr>
<tr>
<td>85+</td>
</tr>
</tbody>
</table>

*NOTE: 6 observations were deleted due to missing values for the response or explanatory variables.

Gender may influence use of hospice (see Survey Question 23). The sample was overwhelmingly female (see Table 10), and ten respondents did not indicate their gender. Gender did not have sufficient predictive power to be used as a control variable.

Table 10

<table>
<thead>
<tr>
<th>Gender</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Income is a likely predictor of use of hospice. Unsurprisingly, however, insufficient respondents (56 of 100) provided income data even in wide income categories. The annual income variable had fourteen respondents state income up to nineteen thousand nine hundred and ninety-nine dollars; twenty-two respondents stated income up to twenty-nine thousand nine hundred and ninety-nine dollars; thirteen respondents stated income up to thirty-nine thousand nine hundred and ninety-nine dollars; seven respondents stated income of forty thousand dollars plus and sixteen respondents had no comment (see Survey Question 25). Over thirty percent of the respondents stated income up to twenty-nine thousand nine hundred and ninety-nine dollars (see Table 11).

**Table 11**

*Annual Income*

<table>
<thead>
<tr>
<th>Annual Income</th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to $19,999</td>
<td>14</td>
<td>25.00%</td>
<td>14</td>
<td>25.00%</td>
</tr>
<tr>
<td>$20,000 – $29,999</td>
<td>22</td>
<td>39.29%</td>
<td>36</td>
<td>64.29%</td>
</tr>
<tr>
<td>$30,000 – $39,999</td>
<td>13</td>
<td>23.21%</td>
<td>49</td>
<td>87.50%</td>
</tr>
<tr>
<td>$40,000 +</td>
<td>7</td>
<td>12.50%</td>
<td>56</td>
<td>100%</td>
</tr>
</tbody>
</table>

*NOTE: 28 observations were deleted due to missing values for the response or explanatory variables.*

The income satisfaction variable had eight respondents very satisfied with their income, forty respondents were somewhat satisfied. Fourteen respondents were satisfied, eighteen respondents were not at all satisfied and one respondent had no comment (see Survey Question 26). This variable had nineteen missing values (see Table 12). This variable described the
population’s income satisfaction; however it did not have enough predictive power to be used as a control variable.

Table 12

Income Satisfaction

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Satisfied</td>
<td>8</td>
<td>9.88%</td>
<td>8</td>
<td>9.88%</td>
</tr>
<tr>
<td>Somewhat Satisfied</td>
<td>40</td>
<td>49.38%</td>
<td>48</td>
<td>59.26%</td>
</tr>
<tr>
<td>Satisfied</td>
<td>14</td>
<td>17.28%</td>
<td>62</td>
<td>76.54%</td>
</tr>
<tr>
<td>Not at all Satisfied</td>
<td>18</td>
<td>22.22%</td>
<td>80</td>
<td>98.77%</td>
</tr>
<tr>
<td>No Comment</td>
<td>1</td>
<td>1.23%</td>
<td>81</td>
<td>100%</td>
</tr>
</tbody>
</table>

*NOTE: 19 observations were deleted due to missing values for the response or explanatory variables.

Many private insurance companies have now instituted a hospice benefit. Insurance plans with these companies vary from coverage similar to and patterned after Medicare, to coverage that reimburses nursing visits or medical procedures but eliminates the psychosocial aspects of care (CMS, 2008).

Some patients are not eligible for Medicare or Medicaid, have insurance that does not include hospice benefits. Many of these patients have assets and can afford to pay all or part of the costs of hospice service. This method of payment is considered Fee for Service Plan. Under this plan, patients are charged on an ability to pay sliding scale.

No one is rejected for hospice care for financial reasons. Patients who do not have insurance, are not eligible for Medicare or Medicaid, and have no assets are provided services without charge (CMS, 2008).
The type of insurance coverage variable varied with the type of insurance coverage. Forty-seven respondents stated they had private insurance. Thirty-five respondents stated they had Medicare coverage. Ten respondents stated they had Medicaid coverage. Four respondents stated that they had Veteran benefits or Champus insurance (see survey question 27). The respondents may have more than one type of insurance coverage. This variable had a total of twenty-eight missing values (see Table 13). This variable described the population’s insurance coverage; however it did not have enough predictive power to be used as a control variable.

Table 13

*Type of Insurance Coverage*

<table>
<thead>
<tr>
<th>Insurance Coverage</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private Insurance</td>
<td>60</td>
<td>40</td>
</tr>
<tr>
<td>Medicare</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Medicaid</td>
<td>90</td>
<td>10</td>
</tr>
<tr>
<td>Veteran's or Champus</td>
<td>100</td>
<td>0</td>
</tr>
</tbody>
</table>

*Percentages of insurance coverage do not add up to 100%; respondents may have more than one type of insurance.

*NOTE: 28 observations were deleted due to missing values for the response or explanatory variables.*
The insurance coverage variable had twenty-six respondents state their insurance covered hospice services. Twenty-seven respondents stated their insurance did not cover hospice services. Thirty-four respondents stated that they did not know if their insurance provided coverage for hospice services (see Survey Question 28). This variable had thirteen missing values. Over thirty-nine percent of the respondents did not know if their insurance covered hospice services (see Table 14). This variable described the population’s knowledge of insurance coverage for hospice service; however it did not have enough predictive power to be used as a control variable.

Table 14

*NOTE: 13 observations were deleted due to missing values for the response or explanatory variables.

Marital status may affect use of hospice. Many African Americans first consult their family circle in making decisions about where to seek help, and show a general reluctance to go outside of their family circle for help with medical care-giving (Harper, 1999). Hospice programs provide a wide range of services based on the needs of the patient and family. It is important to determine the expectations of the patient and family prior to initiating hospice services. The marital status variable had twenty respondents that were single, thirty-two respondents were married, twenty-six respondents were either separated or divorced, and fourteen respondents who were widowed (see Survey Question 29). Marital status is not a predictor of willingness to use hospice. The marital status variable has eight missing values (see
Table 15). Although this variable describes the population’s martial status, it does not have sufficient significance to predict African Americans willingness to use hospice.

Table 15

Marital Status

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single – Never married</td>
<td>20</td>
<td>21.74%</td>
<td>20</td>
<td>21.74%</td>
</tr>
<tr>
<td>Married</td>
<td>32</td>
<td>34.78%</td>
<td>52</td>
<td>56.52%</td>
</tr>
<tr>
<td>Separated or Divorced</td>
<td>26</td>
<td>28.26%</td>
<td>78</td>
<td>84.78%</td>
</tr>
<tr>
<td>Widowed</td>
<td>14</td>
<td>15.22%</td>
<td>92</td>
<td>100.00%</td>
</tr>
</tbody>
</table>

*NOTE: 8 observations were deleted due to missing values for the response or explanatory variables.

Education level was expected to influence use of hospice (see Survey Question 33). Ninety-four out of one hundred respondents answered the educational item. Two respondents stated some schooling, eleven respondents stated they had attended high school, twenty four admitted graduating from high school, twenty-nine respondents had some college education, and twenty-seven respondents revealed they had completed college. Only one respondent had no comment (see Table 16). Although there was considerable variation in educational status, only the distinction between college graduates and non-graduates showed any power to predict use of hospice. Only the dummy variable for college degree was used as a control for educational status.
Table 16

Education

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>8th Grade or less</td>
<td>2</td>
<td>2.13%</td>
<td>2</td>
<td>2.13%</td>
</tr>
<tr>
<td>Some high school</td>
<td>11</td>
<td>11.70%</td>
<td>13</td>
<td>13.83%</td>
</tr>
<tr>
<td>High school graduate</td>
<td>24</td>
<td>25.53%</td>
<td>37</td>
<td>39.36%</td>
</tr>
<tr>
<td>Some college</td>
<td>29</td>
<td>30.85%</td>
<td>66</td>
<td>70.21%</td>
</tr>
<tr>
<td>College Graduate</td>
<td>27</td>
<td>28.72%</td>
<td>93</td>
<td>98.94%</td>
</tr>
<tr>
<td>No Comment</td>
<td>1</td>
<td>1.06%</td>
<td>94</td>
<td>100.00%</td>
</tr>
</tbody>
</table>

*NOTE: 6 observations were deleted due to missing values for the response or explanatory variables.

Multivariate Analysis

Multivariate ordinal logistic regression was employed to explain the likelihood of using hospice (see Table 17). The Score Test for the Proportional Odds Assumption showed no evidence to reject the assumption (Chi-Square =15.07, df=21, p>0.82), allowing a single coefficient estimate for each predictor.

The likelihood of using hospice was predicted by the Mistrust scale (mistrust of formal healthcare providers), the Knowledge scale (knowledge about hospice), and Experience with Hospice (having had a friend or relative in hospice). A variety of controls were considered for the multivariate analysis; but because of the sample size, very few could be used in a
multivariate equation. Accordingly, only those showing the strongest effects on the likelihood of using hospice were included.

Of the one hundred respondents, seventy-five have no missing values on any of the items in the multivariate analysis, with twenty-five missing. On the dependent variable, twenty-one respondents strongly agreed, thirty-two respondents agreed, nineteen respondents were uncertain, two respondents disagreed and only one strongly disagreed that they would use hospice (see Table 3).

**Table 17**

LOGISTIC REGRESSION ANALYSIS:

Odds Ratio @ 95% Confidence Limits

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Point Estimate</th>
<th>95% Wald Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Lower</td>
</tr>
<tr>
<td>Mistrust</td>
<td>0.615*</td>
<td>0.431</td>
</tr>
<tr>
<td>Knowledge</td>
<td>1.549*</td>
<td>1.205</td>
</tr>
<tr>
<td>Friend/Family used</td>
<td>5.428*</td>
<td>1.870</td>
</tr>
</tbody>
</table>

**Control Variables**

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 55</td>
<td>1.159</td>
<td>0.413</td>
<td>3.253</td>
</tr>
<tr>
<td>Male</td>
<td>0.541</td>
<td>0.168</td>
<td>1.738</td>
</tr>
<tr>
<td>Living Alone</td>
<td>0.750</td>
<td>0.246</td>
<td>2.284</td>
</tr>
<tr>
<td>College Degree</td>
<td>0.881</td>
<td>0.310</td>
<td>2.505</td>
</tr>
<tr>
<td>Prayer</td>
<td>1.442</td>
<td>0.504</td>
<td>4.126</td>
</tr>
<tr>
<td>N =</td>
<td>75</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chi Square = 31.90</td>
<td>p &lt; .0001</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Significant at .01 level.
As hypothesized, mistrust of healthcare providers is associated with lower likelihood of use of hospice. The odds ratio for mistrust was 0.62, significant at the .01 level. For each increment in mistrust, there is a large drop (over one-third) in the likelihood of using hospice. This strongly supports the hypothesis of a negative effect of mistrust on likelihood of use. In effect, those African Americans more doubtful about entering hospitals or going to doctors also rate themselves as less likely to use hospice services when needed.

As hypothesized, knowledge of hospice positively predicts use. The odds ratio of knowledge equals 1.55, which is significant at the .001 level. For every point of knowledge increase the use of hospice by over half, strongly supporting the hypothesis. In effect, those African Americans who show greater knowledge of hospice rate themselves more likely to use it.

Also as hypothesized, those with close personal experience of friend or family use of hospice are more than five times as likely to rate themselves as willing to use hospice. The odds ratio of friend or family use of hospice equal 5.43, which is significant at the .01 level. Again, this is very strong support for the hypothesis. African Americans who have known somebody close who has used hospice are very much more willing to report greater likelihood of use of hospice. This certainly highlights the importance of prior experience.

Overall, it appears that African Americans with more knowledge about hospice and more experience with hospice are more likely to use hospice, while African Americans with greater mistrust of formal healthcare providers are less likely to use hospice. Notably, all three hypotheses are strongly supported by the findings. In contrast, none of the control variables: age; male; live alone; and college degree showed significant predictions of likely use of hospice.
CHAPTER 4
CONCLUSIONS

The research findings support all three study hypotheses. It appears that mistrust of healthcare providers among African Americans is associated with a greater likelihood of lower use of hospice. The perspective of mistrust seems to flourish most within a setting where the cultural/racial background of health care workers is not the same as the patients (Haber, 1999). This situation gives more fuel to the cultural mistrust with which a patient may have entered the facility (Reese, Ahern, Nair, O’Faire, & Warren, 1999). Even in cases where hospice workers may enter the home, their presence may not be welcomed into the intimacy of the racial/ethnic family, and viewed with mistrust, especially when they are seen as mainstream health care workers with ties to the mainstream health care system (Gordon, 1984). The dilemma for hospice is that hospice, being what it is in terms of its philosophy, and the makeup of its workforce, is a foreboding place for African Americans. As expected, greater mistrust of healthcare providers in general in the African American community appears to mean lower likelihood of considering hospice a viable option, so contributes to the disproportionately low use of hospice.

At the same time, it appears that greater knowledge of what hospice is, among African Americans leads to greater likelihood of using the service when needed. Lack of knowledge pertaining to hospice in African American communities also impedes access (Neubaur & Hamilton, 1990). African Americans reportedly have lower interest in and knowledge of hospice care than whites (Reese, Ahern, Nair, O’Faire, & Warren, 1999; Harper, 1995; Burrs, 1995). There may also be a lack of agreement with the hospice philosophy among African Americans (Cort, 2004). African Americans see longevity as an intrinsic good, prefer curative care, and
hesitate to welcome strangers from hospice into their homes (Klessig, 1992; Dupree, 2000; Ita, 1995-1996; Gordon & Rooney, 1984). Many African Americans first consult their family circle in making decisions about where to seek help, and show a general reluctance to go outside of their family circle for help with medical care-giving (Harper, 1999). However, the greater the knowledge of what hospice is among African Americans leads to greater likelihood of using the service when needed. Finally, it appears that greater personal experience with hospice on the parts of African Americans, through their friends’ or relatives’ having used the service, increases the likelihood of their own use of hospice services.

Applications

The dilemma for hospice is that hospice, being what it is in terms of its philosophy, and the makeup of its workforce, is a foreboding place for African Americans (Gordon, 1984). The primary goal of service delivery for African Americans is to optimized functioning by providing quality services in the most efficient and effective manner (Green, 1982). Because of shortcomings in the delivery of services, advocacy efforts for radical changes should be engaged (Green, 1982). Protecting African Americans autonomy, providing choices for care for older African Americans and their families, and increasing the accessibility of services that are culturally competent for all groups of older Americans are part of advocacy services (Green, 1982).

Traditional services do not meet the special needs of African Americans with severe mental health disorders, those who are homeless, and African Americans who are developmentally disabled (Green, 1982). With the rapid growth of the aging population, the limited resources available for services provision, and the increasing need for long term care services, policy makers should be challenged to ensure that services to protect the autonomy and
choice of African Americans and their families are culturally relevant and enhance their quality of life (Green, 1982).

Although hospices in the United States accept patients from all religious backgrounds and faith traditions, outreach and increased access for diverse populations is also necessary. Greater understanding of service delivery as well as its impact on patient and family outcomes and satisfaction with hospice care is a critical subject for future research. Changes in Medicare’s reimbursement policies may help hospices increase the range of services provided to African American patients and their families. Knowledge of hospice may prove to be an important predictor of African Americans’ willingness to use hospice. It may overcome some of the mistrust of healthcare providers by African Americans. Knowledge of hospice by African Americans may provide an avenue of intervention to promote hospice in the African American community.

This research results recommend that an important focus of the future be to counsel persons on the availability of hospice as an option for end-of-life care. Well-structured programs of training in cultural awareness and cultural competence throughout the ranks of the health care system must be instituted. When such an effort will pay dividends in reducing cultural mistrust and push closer to eliminating health disparities between minority groups and the rest of society. Providing care at the end of life to African American communities demands communication that crosses cultural divides and the ability to adapt provider services to meet the needs of African American patients, families, and entire communities that may differ from the dominant population. Engaging in culturally congruent care requires that we examine our cultural bias as individuals and healthcare providers, as well as explore the deeply embedded institutional factors that may impede the participation of African Americans in hospice programs. As the patients,
families, and communities continue to become more ethnically and racially diverse, it is incumbent to actively seek cultural information and develop a genuine respect for other cultural world views.

Limitations and Assumptions

Any attempt to generalize the findings of this study should take into account the sample size and the demographic locations. However, as the suggestions for future research indicate, this exploratory study yields many avenues for more in-depth analysis into African Americans disproportionate of use of hospice.

The geographic area from which participants are recruited was limited, which may affect the potential transferability of results. All the participants identified themselves as African Americans. However, the African-American community is quite diverse. This research is limited in knowing which participants have the capabilities to read and understand the responses of the survey. Another limitation is, knowing which participants were being truthful in answering all survey questions. Also Limited is the knowledge of which participants can read and understand the responses. An assumption was; all participants can read the survey questions. Other assumptions were that all participants understood the survey questions and all participants answered all the survey questions. Also, assuming participants answered all the survey questions truthfully.
APPENDIX A

SURVEY QUESTIONNAIRE
Please indicate your response to the following questions by circling your answers.

1. Hospice is a type of care for patients who are close to dying from an illness.
   Strongly agree  agree  uncertain  disagree  strongly disagree

2. Hospice is not a place but a concept of care.
   Strongly agree  agree  uncertain  disagree  strongly disagree

3. Hospice is recognized as the model of quality, compassionate healthcare.
   Strongly agree  agree  uncertain  disagree  strongly disagree

4. Hospice provides healthcare services for people facing life-limiting illness.
   Strongly agree  agree  uncertain  disagree  strongly disagree

5. If I had a terminal illness, I would want to know what it is.
   Strongly agree  agree  uncertain  disagree  strongly disagree

6. I would want to know if I had less than six months to live.
   Strongly agree  agree  uncertain  disagree  strongly disagree

7. My Family would care for me at home if I had a terminal illness.
   Strongly agree  agree  uncertain  disagree  strongly disagree

8. I would rather die in my home than in a hospital.
   Strongly agree  agree  uncertain  disagree  strongly disagree

9. The most important thing to me is to be kept comfortable when dying.
   Strongly agree  agree  uncertain  disagree  strongly disagree

10. Prayer is important when I am dying.
    Strongly agree  agree  uncertain  disagree  strongly disagree

11. I am comfortable being admitted into a hospital.
Strongly agree      agree      uncertain      disagree      strongly disagree
12. I am comfortable using doctors and clinics
Strongly agree      agree      uncertain      disagree      strongly disagree
13. If I had a terminal illness, I would likely use hospice services
Strongly agree      agree      uncertain      disagree      strongly disagree
14. If I had a choice of a healthcare provider, I would prefer to receive services from an
   African American
Strongly agree      agree      uncertain      disagree      strongly disagree

Please use an X to indicate your responses to the following questions.

15. How familiar are you with hospice?
   _____ Very familiar
   _____ Somewhat familiar
   _____ Not at all familiar
   _____ Uncertain
   _____ No Comment

16. What is your religious background?
   _____ Catholic
   _____ Baptist
   _____ Methodist
   _____ Pentecostal
   _____ Jehovah’s Witness
   _____ Other Protestant (please specify) ______________________
   _____ Jewish
17. If you found out that you had a terminally illness and had six months or less to live, do you think you would use hospice services?

_____ Yes

_____ No

_____ Uncertain

_____ No Comment

18. What factors would influence you to use hospice services? __________________

__________________________________________________________________________

__________________________________________________________________________

19. What factors would not influence you to use hospice services? __________________

__________________________________________________________________________

__________________________________________________________________________

20. Have you ever had a relative or friend use hospice services?

_____ Yes (If yes, please go to question 21)

_____ No (If no, please go to question 22)

_____ Uncertain

_____ No Comment

21. Was your relative/friend experience with hospice positive or negative?

_____ Positive

_____ Negative

Please explain ____________________________________________________________
Please use an X to indicate your responses to the following questions.

22. What is your age?
   ____ Up to 18
   ____ 19 -34
   ____ 35- 54
   ____ 55-64
   ____ 65-74
   ____ 75-84
   ____ 85+
   ____ No Comment

23. What is your gender?
   ____ Male
   ____ Female

24. What is your race (ethnicity)
   _____ African American
   _____ Anglo (White)
   _____ Hispanic
   _____ Native American
   _____ Other (please specify) ______________________
   _____ Uncertain

25. What is your annual household income?
26. How satisfied are you with your income?

___ Very satisfied
___ Somewhat satisfied
___ Satisfied
___ Not at all satisfied
___ No Comment

27. Do you have any of the following? (mark all that apply)

___ Private insurance
___ Medicare
___ Medicaid
___ Veteran Benefits or Champus
___ No Comment

28. Is hospice covered by your health insurance?

___ Yes
___ No
___ Do not know
___ No Comment
29. What is your marital status?
   ____ Single – never married
   ____ Married
   ____ Separated or Divorced
   ____ Widowed

30. How many persons make up your household ___________

31. How many persons in your household are under 18 years ____

32. How many persons in your household are 18 years and over ______

33. How many years of education have you completed?
   ____ 8th grade or less
   ____ Some High School
   ____ High School Graduate
   ____ Some College
   ____ College Graduate
   ____ No Comment

34. Do you have any other thoughts or comments about this study that you would like to share?  _________________________________________________________
   __________________________________________________________________
APPENDIX B

INFORMED CONSENT FORM
Before agreeing to participate in this research study, it is important that you read and understand the following explanation of the purpose, benefits and risks of the study and how it will be conducted.

**Title of Study:** End of Life Care: African Americans Disproportionate Use of Hospice

**Principal Investigator:** James Swan, PhD, University of North Texas (UNT) Department of Sociology.

**Purpose of the Study:** You are being asked to participate in a research study which involves the question, “why do African Americans disproportionately use hospice?” The study will explore factors related to African Americans disproportionate use of hospice at the end of life.

**Study Procedures:** You will be asked to complete a survey instrument with instructions and a sharpened lead pencil with an eraser top to complete the survey instrument. The completion of the survey instrument should take only 30 minutes of your time.

**Foreseeable Risks:** No foreseeable risks are involved in this study.

**Benefits to the Subjects or Others:** participation in this research study is expected to assist in understanding why African Americans are reluctant to use hospice at the end of life. Participation may also improved access to hospice care by African Americans at the end of life.

**Procedures for Maintaining Confidentiality of Research Records:** The study results may be published but names and identities will not be revealed. Names and identities will be used on consent forms and to prevent duplicate surveys. The signed consent forms and coded survey results will be kept in a separate location. The confidentiality of your individual information will be maintained in any publications or presentations regarding this study.

**Questions about the Study:** If you have any questions about the study, you may contact James Swan, PhD

**Review for the Protection of Participants:** This research study has been reviewed and approved by the UNT Institutional Review Board (IRB). The UNT IRB can be contacted at (940) 565-3940 with any questions regarding the rights of research subjects.
**Research Participants’ Rights:**

Your signature below indicates that you have read or have had read to you all of the above and that you confirm all of the following:

- James Swan, PhD has explained the study to you and answered all of your questions. You have been told the possible benefits and the potential risks and/or discomforts of the study.
- You understand that you do not have to take part in this study, and your refusal to participate or your decision to withdraw will involve no penalty or loss of rights or benefits. The study personnel may choose to stop your participation at any time.
- You understand why the study is being conducted and how it will be performed.
- You understand your rights as a research participant and you voluntarily consent to participate in this study.
- You have been told you will receive a copy of this form.

________________________________
Printed Name of Participant

________________________________                                ____________
Signature of Participant                                      Date

For the Principal Investigator or Designee: I certify that I have reviewed the contents of this form with the subject signing above. I have explained the possible benefits and the potential risks and/or discomforts of the study. It is my opinion that the participant understood the explanation.

______________________________________                    ____________
Signature of Principal Investigator or Designee   Date
APPENDIX C

INSTRUCTIONS TO PARTICIPANTS
INSTRUCTIONS TO PARTICIPANTS

You are being asked to participate in a survey on attitudes toward hospice care. This research is part of a doctoral student’s dissertation research. Your participation is voluntary. There are no penalties for participation, non-participation, or withdrawing from participation in this research study. You are advised that psychological discomfort may be experienced related to participating in this study. You are encouraged to withdraw without fear of penalty from this research study if these psychological experiences occur. You will have the opportunity to discuss any feelings of discomfort following the completion of the survey. You will be offered the results of the research study when the study is completed. Your participation in this research study may assist in understanding why African Americans are reluctant to use hospice at the end of life. Your participation may also improved access to hospice care by African Americans at the end of life. The study results may be published but your name and identity will not be revealed. Your name and identity will be used on the consent form to prevent duplicate surveys.
APPENDIX D

IRB CERTIFICATE
Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that Ray McDonald successfully completed the NIH Web-based training course "Protecting Human Research Participants".

Date of completion: 07/28/2009

Certification Number: 245876
REFERENCES


Kinzbrunner, B. M. (2002). For profit vs. not-for-profit hospice: It is the quality that counts *Journal of Palliative Medicine. 5,* (4)


