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Nikki Bagli
Addressing Manifestations of
Oppression at End-of-Life Among
African Americans: Unpacking
White Privilege in Hospice Care

ABSTRACT

The U.S. Census shows that African Americans make up 13% of the U.S. population and have higher mortality rates than whites but they only account for 8.9% of the hospice population. This qualitative study examined variables needed to expand hospice services among African Americans, and whether race-based historical injustice needed to be addressed with patients at end-of-life. The investigation is based on the perspectives of seven African American hospice patients receiving in- and out-patient services through one hospice program in the Southeast, U.S. Hospice usage was considered from a relational perspective whereby the cultures of both African Americans and hospice were examined in order to locate the points of both impasse and opportunity. Participants were asked about end-of-life planning, family, spirituality, mistrust, race, values and beliefs surrounding death and comfort so that biases in hospice care which are both overt and insidious would be exposed.

The findings of the research showed that verbally addressing race-based historical injustice was not a necessary component of end-of-life care. Participants reported “trust and care” between workers and patients, which was connected to sincerity, workers’ ability to meet and exceed patient needs and the honoring of spiritual beliefs. Participants recommended increasing outreach efforts among African Americans and physicians proved to be hugely influential in informing African Americans of hospice services. Two key findings emerged from this study: (1) lack of information regarding hospice costs and availability of its services; and (2)

the need for hospice facilities located within African American communities.

**ADDRESSING MANIFESTATIONS OF OPPRESSION AT END-OF-LIFE AMONG
AFRICAN AMERICANS: UNPACKING WHITE PRIVILEGE IN HOSPICE CARE**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2012

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CHAPTER I

Introduction

The purpose of this study is to examine variables needed to expand hospice services among African Americans and to engage African American hospice patients as collaborators in expanding access to hospice care across the African American community. The overriding question for this study was, “How can the culture of hospice be modified to better serve African Americans and does the process involve addressing historical injustice?” This study considered the lack of hospice usage among African Americans from a relational perspective by identifying the culture of hospice and attitudes of African Americans at end-of-life, including the ways in which they are aligned and discordant; and gaining African American hospice clients’ perceptions of how hospice professionals currently negotiate any cross-cultural friction. Findings from this study are intended to provide clinical information on how to more effectively engage the African American community in Hospice services.

The year 2010 saw the first of America’s largest generation of baby boomers approach old age. According to the U.S. Census Bureau, by 2050, 42% of the aging population will be people of color, and people of color of all ages will make up the majority of Americans. Over the next 40 years, the number of Americans aged 65 and older is projected to be 88.5 million, more than double what it is today. One out of every five individuals in the United States will be aged 65 and older; and 21% of these individuals will be aged 85 and older. This group, coined the “oldest-old” is the fastest growing segment of the general population.

Issues surrounding death and dying are gaining national importance in our society. In his review of 2002 State Report Cards, Ervin (2004) showed that 72% of Americans stated that health care improvements for the dying were important to them. The hospice model, which focuses on health care for the dying, has been heralded as an optimal model of care that promotes family and patient-centered care with specific attention to comfort and quality of life for the hospice patient. Yet according to the National Hospice and Palliative Care Organization (NHPCO), 80% of all hospice patients in the United States are white, and African Americans use hospice 40% less than do whites (Ludke & Smucker, 2007; & Greiner, Perera, & Ahluwalia, 2003).

While it is important to examine the accessibility of hospice to patients of all social identities, this study focused specifically on the experience of African Americans who receive hospice care. African Americans have a unique history in the United States that is characterized by slavery, emancipation, segregation, racism and discrimination (Copeland, 2005). African Americans have experienced significant oppression in the United States and when death is imminent, their lived experiences shape their end-of-life decisions, including use of advanced directives. African Americans facing end-of-life may then uniquely require hospice workers to face the racism that has and does define interactions between African Americans and the white health care system, and the ways in which whites have and do benefit from privilege.

Barriers to end-of-life care among African Americans have been widely researched and identified and only recently have tools for the delivery of culturally competent care with African Americans been developed. What is largely missing from the research is the perspective of African American hospice patients on both hospice care and hospice interventions (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Chilton, Wong-Kim, Guidry, Gor, & Jones, 2008;

Copeland, 2005; & Jenkins, Lapelle, Zapka, & Kurent, 2005); and how social, historical and personal experiences shape African American perceptions at end-of-life. Additionally, while much research identifies the culture of hospice as white and middle class, discussions focus on gaining knowledge about African Americans at end-of-life, and rarely include how hospice, as white middle class culture, must and can become culturally aware of itself in order to be more accessible to and effective with people of all social identities. Conflict resolution theorists have long understood that resolution comes through mutual and equal power and vulnerability. The current study argues that through the vulnerable process of self-assessment, hospice will find its resolution to lack of diversity among its patients.

The current researcher proposes that African American hospice patients and their families engage in dialogue not only around their cultural beliefs at end-of-life but also around the culture and practice of hospice. Hence, this study's research was conducted at a small hospice provider with in- and out-patient services in an urban area within the southern part of the United States. Born et al. (2004) showed that family directed decision-making is essential among African Americans; and Mazanec, Daly, & Townsend (2010) added that the extended family structure is important and may include long time friends. Participants in this study were therefore invited to include any member of their support system, who was not a personal employee, and who they deemed essential to their decision-making process in the interviews.

The study is a qualitative, flexible-methods research design with open-ended interview questions intended to gather narrative data from the patients and their families. This research was guided by four questions: (1) how does a hospice worker confront mistrust at end-of-life with African Americans and what affect, if any, does this dialogue have on patient decision-making about and experience of end-of-life care? (2) what are the essential components for establishing

trust in the patient-worker relationship at end-of-life decision-making? (3) of the primary professional providers of end-of-life care (i.e., social worker, doctor, nurse, home health aid, chaplain), which “one” of these providers makes hospice patients feel the most comfortable? and (4) who should be the primary informants or disseminators for hospice services/information in the African American community (i.e., doctors, social workers, ministers, educators, community members)?

Secondarily, this research highlighted the centrality of social workers to the process of providing culturally competent care. Today’s hospice workers are being charged to become social justice advocates, to understand person-in-environment, and to develop dialogical approaches for caring through mutual discussion, education and reflection (Waters, 2000), all of which are practices intrinsic to the social work profession.

This study began with a comprehensive review of literature and was followed by the narratives of seven hospice patients and their families who generously shared their perspectives on hospice care, drawing on some of the most intimate aspects of the human experience.

CHAPTER 2

Literature Review

The purpose of this study was to examine variables needed to expand hospice services among African Americans and to engage African American hospice patients as collaborators in expanding access to hospice care across the African American community. The lack of hospice usage among African Americans was considered from a relational perspective whereby the cultures of both African Americans and hospice were examined in order to locate the points of both impasse and opportunity. The overriding goal for this study was to identify the relevance of addressing race-based historical injustice in health care in expanding hospice among African Americans.

The context for this review of literature was a brief examination of the history and culture of hospice care and included the historical relationship between African Americans and the American health care system. The literature review is divided into two main sections: 1) identifying barriers to hospice care among African Americans, and 2) examining relationally based interventions and recommendations for care with African American older adults. Section one explores barriers to hospice care that are reflective of the cultures of both hospice and African Americans. Section two focuses on the collaborative nature of competent cross-cultural care and recommendations for making end-of-life care more accessible to African Americans.

History of the Hospice Movement

British nurse Cicely Saunders introduced Hospice to the United States more than 30 years ago and it was translated to meet the needs of American society. Hospice was embraced by some as a humane alternative to the alienating, institutional care that was offered to the dying patient during the mid-twentieth century (Buck, 2009). It not only was a model of care but also a reform movement whose leaders' voices became part of the civil rights and peace movements (Buck, 2009). Unlike most medical treatments, hospice care was and is palliative and not curative in nature. Because death is determined to be unavoidable, the care focuses on comfort and quality of life, rather than on sustaining or prolonging life.

Saunders' initial vision of care, which remains today, took into account suffering by physical, mental, emotional, spiritual and social ailments (Clark, 2001). As such under the supervision of a medical director, hospice professionals work in multifaceted teams that are comprised of a social worker, home health aide, chaplain and speech, physical and occupational therapist, to meet the complex needs of hospice patients. Health care professionals have heralded hospice as an optimal model of care, promoting family and patient centered care that focuses on comfort and quality of life. Jones, Moga, & Davie (1999) said, "It [this attitude] responds to what Americans say they want in terminal care: comfort, self-direction, and empowerment; staying at home if at all possible; support for their dying loved ones; and help in avoiding impoverishment during the dying process" (p. 9).

Hospice Care & Public Policy

The National Hospice and Palliative Care Organization (NHPCO) was formed in 1978; by 1979 there was movement to standardize what services comprised hospice care through the Health Care Finance Act (NHPCO, 2010b). In 1982, the Medicare Hospice benefit was passed

solidifying the scope of hospice services and promising greater access to hospice care for all people. While coverage of care did increase access, Medicare's stipulations that hospice patients have a prognosis of 6-months or less, cease all curative treatment, and forfeit traditional Medicare benefits decreased access. "In essence, this provision forced the patient to choose between curative treatment and death, and left the physician with the difficult task of predicting exactly when that death would occur" (Buck, 2009, p. 2705).

The 1990 Patient Self Determination Act, which legally gave patients the right to request or refuse medical treatment, further crystallized the value system that was emerging in hospice care. Staff members of Medicare-certified hospitals and nursing homes were mandated to educate patients about their advance-directive rights. Today, the hospice community views advanced planning for death as an essential component of a "good death". Patients are encouraged to make end-of-life decisions regarding resuscitation and aggressive treatment, to create living wills and advanced directives designed to make the medical community and families alike, aware of their end-of-life wishes prior to their inability to do so.

While hospice was created to respond to the needs of Americans around dying, evidence of that historical impulse to separate the dying continues to linger. As death and dying expert, Dr. Elizabeth Kubler-Ross relays, "Early in my work with dying patients I observed the desperate need of the hospital staff to deny the existence of terminally ill patients on their ward" (1969, p. 251). Hospice challenges a dominant American value around youth and the denial of death and a medical mission to save and maintain lives. So while hospice providers grew to 5,000 in total in 2010, NHPCO showed that only 41.6% of those who died in 2009 were enrolled in hospice. The median length of stay among those who enrolled in hospice was 21 days, while 34% of hospice patients were enrolled for seven days or less. With only peripheral popularity

among the dominant culture, it is no surprise to learn that hospice has done little to implement strategies to improve outreach to non-dominant cultures.

Moreover, hospice care was originally limited mainly to white suburban cancer patients because of regulatory requirements and prognostic uncertainties (Connor, 2007). As cited by Del Rio (2004), Brenner (1997) argues:

it is clear that hospice has been relatively successful in serving middle-class, elderly white persons with cancer who have family members available and willing to care for them at home. Hospices as a whole have not been successful in providing access to *end of life care* to persons and illnesses which diverge from this basic profile (p. 445).

The Administration on Aging shows that of the 39.6 million elderly people living in the U.S. in 2009, 3,286,800 were African American; while according to the NHPCO, of the 1,557,000 who received hospice care in 2009 only 135,459 were African American. In 2010, African Americans made up 13% of the U.S. population and had higher mortality rates than whites but according to the NHPCO, only accounted for 8.9% of the hospice population (Humes, Jones, &, Ramirez, 2010).

Hospice: An Unmarked Culture

Illness, death, dying and grief are all natural and expected aspects of the human experience. While all human beings will face death, the way death is faced varies by culture and personal experience, and is created both personally and collectively. The advancement of medical technology has put human beings in the position of making end-of-life decisions that never before were options and that now place death more in the realm of culture than biology (Koenig & Gates-Williams, 1995). The hospice model has become entwined with the western ethic of autonomy, which is reflective of white, middle-class values and beliefs (Koenig &

Gates-Williams, 1995; Mazanec et al., 2010; Searight & Gafford, 2005; & Yancu, Farmer, & Leahman, 2010).

The legal documents birthed from the hospice culture, such as advance directives and living wills, were developed to sustain autonomy beyond a patient's ability to speak for him or her self. Such documents can be an important and useful tool for families tasked with making heart-wrenching end-of-life decisions for loved ones, especially when family members have opposing or varying beliefs. But for cultures that emphasize connectivity and community and who view autonomy as isolating, these documents are inappropriate and potentially disempowering. The emphasis on autonomy assumes that the individual, rather than the family or social group is the appropriate decision-maker for all people (Mazanec et al., 2010; Krakauer, Crenner & Fox, 2002) when for some, community is the locus of decision-making and "autonomy may violate the very principles of dignity and integrity it proposes to uphold" (Mazanec et al., 2010, p. 563).

Drawing on previous research, Searight & Gafford (2005) identified three aspects of end-of-life care that vary by culture: "communication of 'bad news'; locus of decision-making; and attitudes toward advance directives and end-of-life care" (p. 515). Hospice has specific philosophies that relate to each of these three aspects of end-of-life care, which then limits its accessibility across cultures. The unexamined white middle-class assumptions evident in the implementation of hospice care put hospice providers in a position of blindly alienating those who fall outside of the dominant culture. Yet as Searight & Gafford suggest, when approaching these issues as questions that lead to an understanding of each hospice patient's personal worldview, hospice workers can begin to meet hospice patients of all backgrounds, where they are and in the here-and-now.

History of African Americans and Health Care

As cited by Freeman & Payne (2006), Dr. Martin Luther King, Jr. famously proclaimed, “of all the forms of inequality, injustice in health care is the most shocking and inhumane” (Introduction section, para. 1). African Americans’ relationship with the health care system cannot be separated from this country’s beginnings. Miller and Garren (2008) describe the paradoxical nature of the two contracts that defined the foundation of the dominant culture in the United States:

The social contract stressed the Enlightenment values of equality, citizenship, and human rights, and the racial contract defined who was human and who was not, who was free and who was enslaved, who could be dispossessed of their lands and often slaughtered, and who would take their place (p. 65).

As slaves, African Americans were overworked and under clothed, under fed and under sheltered. While imposed circumstances bred poor health, many doctors refused to see African American patients unless they were forced (Calloway, 1995). Additionally, white researchers not only used African Americans as subjects for medical advancements but they also used research efforts to attempt to prove African Americans an inferior race. Aware of this, slaves avoided reporting illnesses and relied on home remedies and Negro herb and root doctors (Charatz-Litt, 1992). Even during the Civil War, black soldiers died from the same wounds that white soldiers survived. Research like the Tuskegee Syphilis Experiments (1932), which lasted for 40 years, preyed on the bodies of poor African Americans who unknowingly became study subjects, left to die so that doctors could track the progress of syphilis and prevent it in white patients.

Additionally, as cited by Krakauer et al. (2002), as late as the 1960s, women of color in poor

areas were overly targeted for “voluntary” sterilization. These injustices and many more are the lived experiences of today’s African American elderly.

Calloway (1995) refers to these examples as the markings of a “flawed” white physician-black patient relationship, the residue of which not only is felt but enacted today. While these experiences may be less potent for younger generations when they reach old age, poor health care for African Americans continues even throughout the 21st Century. According to the National Center for Disease Control, in 2004, African Americans had the highest death rate of all races/ethnicities, including adjustments for age and causes of death. African Americans also had the highest age-adjusted death rate for heart disease, cancer, diabetes, and HIV/AIDS. African Americans are dying at a faster rate than any other population group in this country. There are many explanations for the health disparities between African Americans and whites, but “Poverty, rather than any specific medical disorder, is the greatest contributor to mortality for blacks and whites,” which make it a social, rather than biological problem (Charatz-Litt, 1992, p. 717).

Death & Dying in the African American Community

As is true of all cultural groups, there are cultural patterns surrounding death and dying among African Americans. While these patterns may represent the beliefs of some African Americans, they in no way represent the views of all African Americans. However, research suggests that people become more connected to cultural patterns at end-of-life (Krakauer et al., 2002 & Kwak & Haley, 2005).

The highly stressful process of dying, perhaps more than any other moment in the course of medical care, can heighten each of these barriers. It can manifest latent cultural

differences, latent racism— individual or institutional, conscious or unconscious—and latent mistrust due to a legacy of racism (Krakauer et al., 2002, p. 186).

While dominant American culture may be characterized by a denial of death, Holloway (2006) explained that for African Americans, “The dead and the ways of our dying have been as much a part of black identity as have been the ways of our living” (Introduction section, para. 5). As further explained by Holloway, for African Americans, death and race are inextricably connected, “the residue of riots, executions, suicides, targeted medical neglect—a range of bodily violence” (Introduction section, para. 1). As such, African American culture, with its many expressions, was born in a space of survival, where values like “not giving up hope, enduring suffering, believing in a ‘higher power,’ and not planning for the ‘unknown’” becomes the sustenance for resilience (Bullock, Christ, & Blacker, 2006, p. 192).

As cited by Crawley & Payne (2006) in the African American community, a paradoxical belief system then surrounds death; it is both an access way to a better place - where life is not marked by injustice; and it is also in itself, an expression of all the injustice endured, and another hurdle to overcome.

Everybody wants to go to heaven, but nobody wants to die. [For African Americans,] it’s not so much the act of dying itself, but the things that are surrounding death: injustice, poverty, mistreatment, and evil . . . We won’t be stopped by those things—it’s our ‘somehow theology’. Some how, some way, we will get through this (Crawley, 2002, p. 775).

In this context, many Christian African Americans view suffering and struggle as redemptive; feelings to embrace, not move away from (Crawley et al., 2000). End-of-life decisions aimed at avoiding pain and suffering may be seen as failing a test of faith. “This ethic

of struggle can be considered part of a moral strength that ensures a better place than this one in a world in which African Americans often die younger than their white counterparts” (Kagawa-Singer & Blackhall, 2001, p. 2997).

Whether spiritually based or not, death, for many African Americans is linked with a life of survival and resilience in the face of adversity that is sometimes guided by a higher power (Johnson, Elbert-Avila & Tulsy, 2005). Quashie (2009) furthers that in the public sphere, resistance has come to define African American culture. This suggests that in order to engage in discussions about end-of-life, hospice workers and health care providers alike, must enter and accept this worldview, portraying hospice not as a means of giving up or doing nothing but of doing something different. Likewise, accepting the worldview of some African Americans’ may mean the white health care system has to come face to face with a dark and gruesome past. In accepting African American cultural beliefs about death and dying, white health care workers must also accept the way white Americans have contributed to and benefited from those deaths. Whether spiritually or politically justified, African Americans’ choice to pursue life-sustaining treatment conveys a spirit of resilience that says you will not ‘white’ me out this time. Unless hospice workers actively engage in dialogues that honor this belief system and which makes hospice something other than a choice to die, they inadvertently support the idea that hospice equals death and the pursuit of life will remain unbending.

Barriers to Hospice among African Americans

The researcher examined articles published between 1995 and 2011 on barriers to end-of-life care among African Americans. From these articles, the researcher identified 11 factors that are supported and interpreted by a variety of researchers in a number of different ways: Medicare Eligibility Requirements (Born et al., 2004; Cort, 2004; Di Sorbo, 2011; & Reese, Ahern, Nair, O’Faire & Warren, 1999); Insurance (Cort, 2004; & Krakauer et al., 2002); Spirituality (Born et

al., 2004; Branch, Jr., Torke & Brown-Haithco, 2006; Braun, Ford, Beyth & McCullough, 2010; Bullock et al., 2006; Jenkins et al. 2005; Johnson et al., 2005; Johnson, K. S., Kuchibhatla, M. & Tulskey, J. A., 2008; Kagawa-Singer & Blackhall, 2001; Mazanec et al., 2010; Reese et al., 1999; Washington, Bickel-Swenson & Stephens, 2008; & Waters, 2001); Access/Exposure (Allen, Allen, Hilgeman & DeCoster, 2008; Born et al., 2004; Burr et al., 2008; Enguidanos, Kogan, Lorenz & Taylor, 2011; Ervin, 2004; Jenkins et al., 2005; Johnson, Kuchibhatla & Tulskey, 2009; Kwak & Haley, 2005; Ludke & Smucker, 2007; Reese et al., 1999; Rhodes, Teno & Welch, 2006; & Washington et al., 2008); Economic Factors (Born et al., 2004; Cort, 2004; Reese et al., 1999; Washington et al., 2008 & Waters, 2001); Preference for Life Sustaining Treatment (Allen et al., 2008; Braun, Beyth, Ford & McCullough, 2008; Braun et al., 2010; Cort, 2004; Duffy, Jackson, Schim, Ronis & Fowler, 2006; Enguidanos et al., 2011; Johnson et al., 2008; Kagawa-Singer & Blackhall, 2001; Kwak & Haley, 2005 & Reese et al., 1999); Dominated by white Hospice Staff (Braun et al., 2010; Cort, 2004; Jenkins et al., 2005; Mazanec et al., 2010; Reese et al., 1999; & Washington et al, 2008); Location (Mazanec et al., 2010); Family Framework (Born et al., 2004; Burr & Gerst, 2008; Bullock et al., 2006; Cort, 2004; Ervin, 2004; Jenkins et al., 2005; Kwak & Haley, 2005; Ludke & Smucker, 2007; Mazanec et al., 2010; Washington et al., 2008; & Waters, 2001); and Mistrust (Armstrong et al., 2008; Born et al., 2004; Braun et al., 2010; Burr & Gerst, 2008; Bullock et al., 2006; Calloway, 1995; Cort, 2004; Crawley, 2002; Enguidanos et al., 2011; Ervin, 2004; Johnson et al., 2005; Johnson et al., 2008; Kagawa-Singer & Blackhall, 2001; Kwak & Haley, 2005; Mazanec et al., 2010; Reese et al., 1999; Washington et al., 2008; Waters, 2000; & Waters 2001) were all named as important factors contributing to health disparities. However for purposes of this study, the researcher focuses on the most widely

identified factors: Family Framework and Mistrust. Research on family framework is used to guide the frame of this study and mistrust is used to guide to the content.

Family as a Barrier to Hospice Care

Born et al. (2004) conducted four focus groups with African Americans (4 groups, n = 26) drawing themes through consensus and triangulation, determining that inclusion of family was central during the dying process and that it is specifically the role of spouse and children to care for the ill. Family directed decision-making also proved to be essential. A major concern was caregiver support and an interesting paradox that emerged was that the same family member who was committed to caring for their loved one, did not want to burden their families if they fell ill. This finding also was supported by Braun et al. (2008). In their analysis of previously studied work, Washington et al. (2008) also highlighted the fear of family caregiver burn out among African Americans.

Mazanec et al. (2010), supported these findings, explaining that for African Americans, family, faith, community, and the health care system interact equally to shape decision-making, suggesting that interventions must address all of these facets in order to be both received and effective. They also make note of an extended family structure including long time friends, which is different from the dominant culture's attachment to the nuclear family. Although Ervin (2004) simply identified the importance of educating both patients and families, this inclusion of family again suggests that family is a major part of the decision-making process.

Cort (2004) echoed the central role of family among African Americans noting that when seeking medical attention, African Americans generally refer only to family members for direction. Through telephone interviews with 473 adults (220 blacks, 253 whites), Ludke & Smucker (2007) illuminated the importance of family among African Americans by determining

that their perceptions of hospice were based on the experiences of family and friends. Especially poignant within the research were the vastly different approaches the qualitative studies took to arrive at the same conclusion.

The central role and extended nature of African American families is well known and it is clear that this cultural consideration must be taken into account when making African Americans aware of choices at end-of-life (Goldenberg & Goldenberg, 2008). Information that is only presented to the patient and not to the family and services that are patient and not family-centered will likely be rejected. These findings speak specifically to a desire among African Americans for end-of-life support, but with the presence and integration of family. It is possible that African American families may be more inclined to adjust traditional caregiving beliefs and practices if hospice programs also adjust to their cultural frameworks. The current research is intended to support family interventions as a new best practice standard among hospice organizations and professionals.

Mistrust as a Barrier to Hospice Care

Even more widely cited than the importance of family, was mistrust for the health care system among African Americans. While it is heavily emphasized in most research, what varies is how mistrust is being defined. Reese et al. (1999) created a Hospice Barriers Scale that led to a Hospice Beliefs and Attitudes Scale that is still highly utilized among researchers today. Adding to that, Armstrong et al. (2008), used social psychology to define two dimensions of trust: values and competence. Even when adjustments were made for sociodemographic factors and insurance, mistrust was connected to values and lived experiences, not doctor competence. Mistrust is therefore defined not around a doctor's ability but around perceived differences in values based on race and culture.

Crawley & Payne (2006) focused on the important difference between dispositional and situational mistrust and the risk of “blaming the victim” inherent in dispositional thinking. Dispositional trust refers to a cultural value that is not based in experience while situational trust is process oriented and built in experiences over time. Regarding African Americans’ mistrust of the health care system as situational, acknowledges the role that the health care system has in perpetuating the mistrust, and thus makes their role in the process of reversing mistrust equally evident.

Situational-based research like that of Reese et al. (1999), which couches the discussion of mistrust in terms of historical injustice in the health care system, describes the process by which mistrust was developed. As one of eight studies (Armstrong et al., 2008; Chilton et al., 2008; Cort, 2004; Johnson, Elbert-Avila, Kuchibhatla & Tulskey, 2006; Kagawa-Singer & Blackhall, 2001; Mazanec et al., 2010; & Volandes et al., 2008) that mention the affects of the Tuskegee Study on African American elderly today, they noted, “one respondent indicated a reluctance to seek medical treatment, lest he or she ‘end up being a guinea pig in one of their experiments’” (Reese et al., 1999, p. 554). Waters (2000) described how from this view, advanced directives are perceived as death warrants instead of a tool for ensuring health care wishes are respected beyond a person’s ability to represent them. Through focus groups, Waters (2001) further found that African Americans worried that advanced directives would cause insurance companies to deny them or reject coverage for life-prolonging medical procedures. With a quote from a vocal community leader, Bullock et al. (2006) further captured this sentiment: “As a black man, I am subject to receive less care and attention than a white man, and if I had a living will, they might not care for me at all” (p. 192).

The mistrust of white people who are in the position of making life or death decisions for

African Americans is exemplified by a focus group participant on end-of-life decision-making in recent research conducted by Waters (2001):

I'm concerned about White people making decisions for me because I know the decisions that they've made over the last 300 years concerning Black people. If they're making decisions on a Black person coming to the hospital and spending a dime more for them, I think they would cut all services. I think people triage on the basis of race, class, sex, and injury. We are dying because of benign neglect (p. 391).

Cort (2004) linked this attitude to a desire for life-sustaining treatment adding, "Might it not then be reasonable to 'go down fighting' if one's death is part of a perceived pattern of social injustice?" (p. 64). He postulates that mistrust for the health care system in African Americans' is equal to their general mistrust of white Americans and the traditional American system. In the medical setting, Cort described how this mistrust is associated with less satisfaction with services, which is then linked to recovery process, putting African Americans at a recovery disadvantage.

Cort (2004) explained that what is perceived as a barrier among African Americans by some health care professionals, may actually be a coping strategy employed for survival in a hostile environment. Crawley et al. (2002) described this as "going down fighting," and highlighted the logic in resisting even a "good death" when access to basic preventive services and treatment were limited by institutional racism. Kagawa-Singer & Blackhall (2001) articulated the duality of mistrust and how essential it is that quality care accompanies an increase in trust for the health care system among African Americans. "Simply encouraging African Americans and other ethnic minorities to be more 'trusting' of recommendations

provided by European American physicians is doomed to failure” (Kagawa-Singer & Blackhall, 2001, p. 2996).

Mazanec et al. (2010) further supported the relationship between historical injustice and mistrust, referencing medical practices against African Americans as early as during slavery. They also explored the manifestations of these belief systems today: “In cancer care, many African Americans prefer to continue with chemotherapy even if the benefits of the treatment are minimal. The desire for the ‘latest treatment’ may be related to the same historical context of social injustices previously described” (p. 561). The implications then, for hospice care, are that African Americans are not choosing this service because the quality of care they desire is shaped by experiences of past and present racism that has prevented access to superior health care. African Americans are then defining best treatment procedures in terms of those that sustain life even if outcomes are not positive. Because hospice requires patients to discontinue aggressive treatment, it is in direct opposition to an African American client’s desire to maintain life and to resist the injustice of death.

Drawing on the literature and the situational mistrust paradigm, creating trust and an openness to hospice services among African Americans lies in both addressing historical mistrust and also providing trustworthy services in the present. African Americans and the health care system are in a constant state of mutually recreating the reality of the experience for African Americans in health care today and this reality is informed by the inextricable connection between the past and the present. Without addressing this mistrust that is both justified and prevalent among African Americans and providing services that are worthy of trusting, it is unlikely that hospice will be considered an end-of-life care option for this population group and

they will miss out on a service that society deems as vital (Armstrong et al., 2008, Mazanec et al., 2010, & Copeland, 2005).

Cultural Competence at End-of-Life

As the United States grows in diversity, so too does the likelihood for multi-cultural medical encounters and the risk of cross-cultural misunderstandings surrounding care (Kagawa-Singer & Blackhall, 2001). Though the culture of hospice is reflective of dominant western culture, Dr. Cicley Saunder's original goals of hospice, as cited by Rhodes, Teno & Connor (2007), remain an important guide for health care professionals in connecting with patients across cultures: "...Commitment to openness, openness to challenge, and the absolute priority of patients' own views on what they need" (p. 476). These goals are fully applicable to a new vision of cultural competency put forth by Kumaş-Tan, Beagan, Loppie, MacLeod & Frank (2007):

...one of culturally diverse health professionals serving culturally diverse patients, sharing their knowledge while learning from and with patients, and bravely acknowledging, recognizing, and challenging the many forms of oppression that produce the enormous disparities in health and well-being we witness today (p. 555).

As cited by Krakauer et al. (2002), "Physicians first must recognize that the basic values, principles, and assumptions of western medicine and bioethics are themselves historically situated and culturally determined" (p. 186). Hospice professionals must do the same to effectively deliver services to a diverse range of people. In order to make hospice accessible to African Americans, health care professionals must not simply seek to gain knowledge about African Americans' barriers to hospice care or beliefs and practices around death and dying, but more importantly, they must be willing to focus their attention on their own privilege and the ways in which they collude with a system, which has and does favor some people over others.

Further, as an institution, hospice must be willing to acknowledge and change its own invisible culture. As Del Rio (2004) asserts, changes to personal worldviews must also be accompanied by a systematic transformation that requires "...looking at the policies, laws, practices, rules, norms, procedures, and values that function to the advantage of one group and the disadvantage of another" (p. 447).

In one of a few articles that address the subject of cultural competency specifically as it pertains to end-of-life, Reese, Melton & Ciaravino (2004) framed their discussion around barriers within the health care system as opposed to barriers within African American culture. In doing so, they also identified the problems and solutions of racial disparities in hospice use in the health care system itself and not in the cultures of people of color. Their perspective acknowledges how hospice policies and procedures, which are aligned with dominant culture invisibly characterize communication, making it essential that health care professionals become culturally aware personally and institutionally so that their conception and communication of options are not unknowingly biased by any particular worldview (Reese et al., 2004).

Communication

Volumes of research discuss the importance of health care professionals acting from an awareness of African Americans' history within the health care system and an openness to having the difficult conversation about the social inequities that underlie this history (Calloway, 1995; & Mazanec et al., 2010). Elioff (2003) described this as cross-cultural empathy and proposed that more must be done to promote empathy on hospice teams. While empathy is of key importance, this thinking allows workers to maintain a posture of privilege and does not challenge the concept that one group's reality is being favored over another's. In their discussion on what cultural competency actually is and how it can be measured, Kumaş-Tan et al. (2007)

suggested that health care professionals adopt a perspective whereby “difference” triggers a consideration of social power *dynamics* as opposed to pursuit of knowledge about the other.

Though Borreani et al. (2008) did not focus on the role of culture in decision-making; they underscored the need for tools that communicate preferences about dying. They pointed to the importance of inquiry and sensitivity and drew on a list of thematic areas to guide doctors in connecting with their patients around end-of-life issues from Steinhauser et al: physical symptoms, preparation of end-of-life, completion about one’s life, clear decision-making, being treated as a whole person and contributing to others. According to Borreani et al., the doctor becomes a facilitator and their leadership is a relational instrument. Their work not only has implications for working with African Americans but also speaks to the sensitivity required in working with any person facing end-of-life.

Braun et al., (2010) expanded on this concept, adding that the end-of-life decision-making process should be tailored in response to the patients’ race/ethnicity. Their qualitative study is one of few that examined physician perspectives on the impact of culture on end-of-life. Among the 26 doctors interviewed, African American physicians provided particularly poignant insight into working with African American patients that corresponds with what studies demonstrate is important to African Americans at end-of-life. They emphasized the significance of creating trusting relationships so that they could become the family’s “guidance counselor.” This again points to the importance of being a facilitator, who draws out the needs of families at end-of-life and relates them to their end-of-life options.

As participants in African American and Medical cultures, African American doctors became translators between these two cultures. This ability to place end-of-life choices not only in the context of African American culture but also in the personal culture put forth by each

individual, is exactly what must lead hospice workers in their pursuit of excellent culturally competent care. Elioff (2003) and Cort (2004) supported this thinking, and recommended that hospice team members try to understand the fears and mistrust of African American patients who come to them in their delivery of care.

African American doctors also spoke of understanding what terms like “doing everything” mean and the importance of redefining hospice not as “doing nothing” but as providing something different: comfort care. If African Americans perceive hospice care as death, a bi-product of Medicare’s eligibility requirement to cease curative treatment, then those who put their life in God’s hands, who resist oppression through struggle, who have been repeatedly denied services, cannot possibly see hospice as an option unless it is framed this way.

Braun et al. (2010) also showed that many doctors, particularly white ones, felt uncomfortable initiating end-of-life discussions. When these discussions are with patients of a different race and include acknowledgement of historically based mistrust, another layer of discomfort is added. Doctors and African Americans can easily collude around their pursuit of life. It is possible then, that in the context of end-of-life, prejudicial treatment lies in doctors extending care beyond its ability to have a positive impact, where again African American bodies are subjected to painful interventions that do not enhance, but limit life.

In creating cross-cultural empathy clinicians also must create a deeper personal awareness. As is true of therapeutic interactions, “When cultural countertransference is disavowed, the therapist is better able to co-create a therapeutic experience that is effective for the client (Keenan, 2001, p. 223). Moreover, the benefit to understanding the patient is further understanding one’s self. Kagawa-Singer & Blackhall (2001) poignantly captured this with the following quote from an African American male hospice patient:

Well, you know, you got to find out the identity of a person to even get to know them. So I think that's a big "if" right there. Because if you don't know a person, you got to find out his identity, go where he lives, where he goes, where he was born, who's in his family. And he's got to open up, and tell you these things. Because the more you know about this person, his family, then that'll make you know more about you (p. 2993).

Still, providing culturally competent care is not purely interpersonal. Knowing when and with whom to engage and partner with from the community is another way to successfully expand programs.

Education and Outreach at End of Life

Allen et al. (2008) whose work focused on the importance of decision-making aids at end-of-life showed that when African Americans were presented more information, their desire for life sustaining treatment decreased. Volandes et al. (2008) supported the need for increased health literacy and a commitment to patient education and communication, but asserted that it should be the focus of research as opposed to race. They found that the vast majority of their study subjects across all races and health literacy levels chose comfort care after viewing information on end-of-life choices by video.

In contrast, Enguidanos et al. (2011) tested the use of culturally specific hospice outreach materials. Based on the success role model stories had in educating African Americans on HIV/AIDS risk, they created a hospice brochure depicting the stories of African American hospice patients and their families. They tested the effectiveness of role model stories in improving attitudes toward and increasing enrollment in hospice care among African Americans and found that after reading their brochure, attitudes toward hospice care improved. The number of people willing to seek hospice care for themselves also increased 12.7%. But in congruence

with the research of Reese et al. (1999), Mazanec et al. (2010) and Cort (2004), the belief in pursuing life sustaining treatment persisted.

The use of video may then be another effective way to reach African Americans by including their voices in the delivery of hospice information. The often white race of medical professionals is a widely cited source of distrust among African Americans and it may further the notion that hospice care is not for African Americans. Through video, health care professionals can depict the experiences of existing African American hospice patients or the family members of past hospice patients, which may make hospice a more accessible option.

The Role of the Social Worker

Research citing discrepancies in hospice usage between whites and people of color can be found as early as the 1990s, as can recommendations for increasing diversity and accessibility in hospice care. Still, decades later, only 20% of the hospice population is made up of people of color. The issues that arise between patients and workers of cross-cultural backgrounds in hospice are a microcosm of a health care institution steeped in white culture and privilege. If addressing historical injustice is an important aspect of conversations that must be had with African Americans when navigating end-of-life choices, then hospice workers are being asked to perform a task that the health care institution has not itself tackled or mastered.

Discussion around racism and injustice is rarely easy no matter what the setting or the background of the people having it. These conversations are painful and shaming for both people of color and white people. If any profession can claim to specialize in the art of navigating difficult conversations around oppression of all kinds, it is social work. As evidenced in the National Association of Social Work (NASW) Code of Ethics, social workers “focus on individual well-being in a social context”, and particular attention is given to “the needs and

empowerment of people who are vulnerable, oppressed, and living in poverty”; social justice and social change are intrinsic to the work in its many forms. Further, social workers are required to have self-awareness. Beginning education in social work focuses on familiarizing new social workers with their own values, beliefs and identities and the ways that biases may distort the way people of the same or other cultures are perceived (Hays, 2009). Social Workers then have unique knowledge, not around what African Americans may want or need at end-of-life but on how to listen for those needs as they pertain to both cultural and personal belief systems.

According to the NASW Center for Workforce Studies & Social Work Practice (2010) hospice social work functions include:

Counseling and psychotherapy for individuals, couples, and families; Providing psychosocial education to patients and family caregivers about coping skills, hospice and palliative care philosophy, and nonpharmacological symptom management strategies; Providing in-services to other service providers and organizations; Leading community education workshops; Planning for discharge, coordinating care, and helping clients navigate systems; Facilitating advance care planning and lifespan planning; Intervening in crises; Mediating conflicts within families, between clients and the interdisciplinary team, and between service organizations; Participating in interdisciplinary team meetings, care planning, and ethics consultations; Advocating on behalf of the patient and family; Identifying and linking clients with resources; Facilitating psychoeducational support groups; and Documenting social work activities.

This researcher asserts that social workers also must become leaders on hospice teams and organizations in evaluating and developing practices and procedures that are cross-culturally appropriate.

Summary

End-of-life is a deeply intimate and personal time for anyone; accompanied by sights, sounds and feelings never experienced otherwise. It is a universe unto its own and hospice care attempts to develop a foundation for guiding people through that process, which society has deemed as important and optimal. The foundation however, is accompanied by a value system – an unmarked content reflective of dominant culture’s beliefs surrounding dying – that unknowingly alienates those who fall outside of the dominant culture. But if the hospice adage that you “die the way you live” is true, than culture has everything to do with the way death is experienced and end-of-life services must be open to the cultures of all people. As the research conveys, for African Americans life and death have been linked with injustice. By not creating a central forum in which race and racism can be discussed at end-of-life, or within the health care system at large, health care professionals are not only allowing racism to shield access to an important end-of-life service but are again, perpetuating racism in providing a service that is only culturally appropriate for some.

Many research studies have attempted to force the existing approach on African Americans and come back with the same statistics and reports: African Americans utilize hospice 40% less, they have fewer ‘Do Not Resuscitate Orders’ (DNR), fewer advanced directives and living wills and more Cardiopulmonary Resuscitation (CPR) orders, and are more inclined toward aggressive treatment. Few studies however, present the voices of African Americans at end-of-life. When Jenkins et al. (2005) interviewed relatives of African American hospice patients on their preferences for end-of-life discussion with health care professionals, they used words like “nurture”, “protect”, and “make eye contact”. In contrast to studies that say hospitals are preferred by African Americans these participants also preferred to die at home.

The way hospice information is delivered is equally as important as the information itself and the qualities of care that instill trust and comfort in African Americans are reflective of basic human needs.

Moreover, as the literature demonstrates, in order to make hospice care accessible to African Americans, it is necessary not just to understand the culture of African Americans at end-of-life but to understand the culture of hospice. Hospice is founded on a belief about what a “good death” means. Therefore, when a patient who defines “good death” differently than hospice does comes in contact with hospice, there is an impasse centered on a refusal by both parties to accept the other’s definition. As long as hospice is guided by content and not a form driven belief system it will have limited access to anyone whose belief system varies. As it is the therapist’s role to be aware of their own biases and to know but hold loosely the cultural beliefs of their patients, hospice is challenged to begin recognizing itself, and to create a space that acknowledges and removes bias as much as is possible. And in relation to African Americans, if this involves addressing race-based historical injustice; it is an important opportunity for healing not only for African American patients but for hospice workers of all races as well.

The next section contains the Methodology of the study followed by the Findings from seven qualitative interviews with African American, male and female hospice patients aged 18 years and older and receiving services from one hospice program through their in and out patient units.

CHAPTER 3

Methodology

The purpose of this study was to determine how hospice can make itself more accessible to African Americans and to establish whether alleviating mistrust of hospice among African Americans involves directly addressing race related historical injustice. Drawing on previous research about the culture of both hospice and African Americans at end-of-life, this study examined the relevance and impact formal end-of-life planning, family, spirituality, historical injustice and beliefs around dying have on trust building and comfort at end-of-life among African Americans. Findings from this study are intended to provide clinical information on how hospice services can be expanded to more effectively engage the African American community.

The information and data was obtained from both male and female African Americans who were 18 years of age and older and were currently enrolled in hospice. Initially the study population consisted of African Americans, aged 65 years and over but due to the vulnerability of this group and challenges in gaining respondents who were emotionally and physically able and or interested in participating, the age range was expanded. Any unpaid member of the identified patient's support system whom he or she deemed essential to the end-of-life decision-making process was able to participate in the interview at the patient's discretion. The current research is intended to support family interventions as a new best practice standard among hospice organizations and professionals. By both including family members in interviews and

asking questions about the importance of family inclusion, this research is expected to support the empirical evidence confirmed by the current literature review.

The study was a qualitative, flexible methods research project, using open-ended questions to gather narrative data. This research method was employed because of its ability to aptly capture the essence of the subject's experience through his or her own words and actions (Anastas, 1999). This researcher obtained data through an Ethnopolitical Psychology paradigm that views a person in terms of the psychological affects of oppression, racism, terrorism and political repression, acknowledging the contextual reality of a person's experience and thereby creating space for liberation (Comas-Diaz, 2000).

Because the research process so closely mimics the cross-cultural experience between the hospice patient and hospice worker, the researcher, who is a white female, aimed to be consistent in both the form and content of this study – approaching interviews from a stance of “informed not-knowing,” by which this researcher acknowledges cultural practices among African Americans without essentializing African Americans (Laird, 1998). Borrowing from the Community Based Practice Research model, this researcher managed diversity by relating to hospice patients as equal collaborators “who are seen not as ‘othered’ challenges, obstacles or problems for “our work”, but rather as sources of opportunity for knowledge and policy enrichment (Cohn & Eckenwiler, 2007, p. 254).

Sample

This research was conducted in the southern state of Georgia where there is a large African American community. According to the NHPCO's National Summary (2009), in Georgia 78.5% of hospice candidates are 65+, while 43% are male and 56.1% are female. A non-probability sample of availability was used to find research subjects who matched these criteria.

Due to the highly vulnerable and intimate nature of hospice care, finding participants of either gender was difficult. This researcher intended to interview 15 patients but due to time constraints, mental and/or physical status and outside decision-making, only eight participants were secured, one of which withdrew from the study. Additionally, many of the patients interviewed were at such advanced stages of illness and/or were on pain medications that their cognition and or physical functioning were weakened making it difficult for some of the participants to remain fully alert for the entire interview.

Research took place at a small local hospice program with an inpatient and outpatient unit that is owned and operated by a couple of color, one of which is an oncologist. The facility is located in a predominantly African American community and serves predominantly African American patients. This hospice was selected because several of the major barriers regarding the race of patient, staff and administration, as well as geographic location, were minimized. In the absence of these barriers, this researcher thought there would be greater opportunity for trust and safety among African Americans in care and a lesser possibility of cultural mis-attunements between hospice culture and African American patients. It was thought that in this context, patients would be able to offer new insight into how to create culturally competent programs.

The researcher worked with the hospice administration and teams to recruit research participants. Two venues for recruitment were utilized: (1) Service providers and staff (i.e., social workers, doctors, nurses and other members of the interdisciplinary team) verbally informed existing patients about the study and their potential to volunteer for participation; and (2) flyers, word of mouth discussions, and snowball sampling (referrals for participation made by friends, family, current participants, etc.) were made available. (See Appendix E for flier illustration).

Ethics and Safeguards

Due to the fragile health of participants, the interviews were conducted in person, in the location where the participant received their hospice care (private home, nursing home, assisted living facility, hospital or hospice). This researcher was accompanied by a hospice staff member during all in home interviews and hospice patients were given the option of including them and/or having them present in the room while the interview was being conducted. While this further ensured physical safety for the patient and the researcher, the data may also have been skewed by the influence of having a member of the hospice team present while evaluative questions were being asked. With the permission of each participant, the interviews were audio recorded. In keeping with federal regulations and the ethics of the social work profession, the findings of this study do not reveal identification of the study's participants. A numerical code was assigned to each participant and data was summarized shielding all information about individuals' identity. All quotes and illustrative vignettes have been written in a manner that does not reveal information that could identify participants. According to federal guidelines, all notes, transcripts, audio-recording, and informed consent information is securely locked in an unidentified location for three years, with access only by the researcher.

The purpose and design of the research project, including the benefits and risks of participation were explained to each participant. The researcher informed all participants that their participation was voluntary and that all information gathered would be held with strict measures of confidentiality per Federal Guidelines. The researcher further informed participants that they could withdraw from the study at any time during the interview or anytime before March 31, 2012, and that all their information would be destroyed. Participants also were informed that in cases of group interviews, unless they were the identified patient, it was not

possible to withdraw data pertaining to one individual from the audio-recording due to the connectedness in the flow of the conversation, making it difficult to extract one member's voice from the collective tape recording.

Participants were informed that there would be no financial compensation for their participation in this study. They also were informed that although there may not be direct benefit to participation in this study, their valuable perspective might contribute to the overall body of knowledge on how to better serve African Americans at end-of-life. They also were informed that information provided may enlighten future hospice practices as well as provide insight for outreach to other African Americans who could benefit from participation in the hospice program.

Although a commonly reported aspect of mistrust in health care among African Americans is the lack of diversity among health care providers, this researcher chose to conduct the interviews personally. This researcher expected to meet some of the same challenges as any hospice worker who works with a patient of a different race or ethnicity. Because this researcher is largely reflective of hospice staff nationwide, and the purpose of this study is to enhance multiethnic discussions and experiences at end-of-life, the interview process itself, was viewed as an opportunity to further the use of culturally competent clinical practice in hospice care. The researcher acknowledged race in the room, freely discussed her interest in this subject matter and invited open dialogue on how social identities may or may not affect the experience for each family.

Data Collection

The Smith College School for Social Work Human Subjects Review Committee approved this study (see Appendix B) as well as the expansion of the age group included.

Participants were provided the informed consent (see Appendix C & D) at the time of the in-person interview and were again asked to verbally confirm consent. The researcher reviewed the consent form with each participant prior to beginning the interview.

Data collection was obtained through semi-structured interviews that ranged between 10 and 40 minutes, depending on the number of persons present for the interview and the length and consensus of their answers. Time also was predicated upon the participants' ability to respond and their ability to complete the interview. Participants were informed of the focus of the research and its attempts to improve cultural competence among race discordant hospice workers. This research was guided by 10 broad questions (see Appendix D). This guide was designed to become more specific as the discussion progressed, and additional questions were asked as necessary to expand upon issues or probe into areas for clarification (Waters, 2001).

Data Analysis

Participant characteristics were captured through descriptive statistics regarding family, gender, marital status, age and education to determine whether beliefs and values remained consistent when adjustments were made for these factors. Responses to the interview questions were coded and analyzed manually by emergent themes and organized by both research and interviews questions. Attention was paid to both latent and manifest content and hierarchical coding was used to label concepts that were ambiguously defined.

CHAPTER IV

Findings

The purpose of this study was to examine how the culture of hospice can be modified to better serve African Americans and to determine whether addressing historical injustice is integral to this process. The findings in this section are based on seven interviews conducted with African American hospice patients. Interview questions were designed to gain the perspectives of African Americans on their experience of hospice and the factors that most greatly impacted their trust and comfort. Interviews began by soliciting demographic information about the participants including: gender, marital status, age, education, residence type and length of hospice enrollment. Additionally, when support persons were present, their relationship to the patient and occupation also were collected. Occupation data was meant to distinguish people in helping professions, which might make them privy to hospice knowledge. Information regarding the completion of end-of-life care planning was also collected and will be included under its own heading.

The remaining data was organized by research questions: (1) how does a hospice worker confront mistrust at end-of-life with African Americans and what affect, if any, does this dialogue have on patient decision-making about and experience of end-of-life care? (2) what are the essential components for establishing trust in the patient-worker relationship at end-of-life decision-making? (3) of the primary professional providers of end-of-life care (i.e., social worker, doctor, nurse, home health aid, chaplain), which “one” of these providers makes hospice

patients feel the most comfortable? and (4) who should be the primary informants or disseminators for hospice services/information in the African American community (i.e., doctors, social workers, ministers, educators, community members)?

Demographic Data

This chapter includes the responses of seven African American who were enrolled in hospice at the time of the interview. Because there were originally eight participants and Participant 2 withdrew from the study, data will convey the experiences of participants 1 and 3 through 8. In congruence with the population, four of the participants are female and three are male. Participants are between the ages of 51 and 79 with the average age being 66 years old. Four of the participants were outpatient, of which three lived in private homes and one in an assisted living facility. Three of the participants were receiving care in the hospice's inpatient unit. Participants had been enrolled in hospice between two days and five years. Two participants were in hospice for two days to one month (n=2), two for six months to one year (n=2) and three were enrolled for one to five years (n=3). Three of the participants were married, two were divorced, one was widowed and one was single. Participants were in school between seven and 16 years, and on average had completed high school.

A support person was present at two of the interviews conducted. One of the support persons was a daughter whose occupation was not provided. The other was a sister who reported being currently unemployed. Both support persons were also power of attorney for the patient. Of the three participants who were outpatient, an employee of the hospice was present for the interview to ensure safety for both participants and this researcher.

End-of-Life Care Planning

Because research has identified end-of-life paperwork as a barrier to hospice care, participants were asked to report on the end-of-life planning they had undertaken. In congruence with current research, nearly half of participants (n=3) had completed Advanced Directives and Living Wills. While contrary to research, more than half of the participants (n=4) had Do Not Resuscitate (DNR) orders. However, two of these participants openly considered reversing their order. Two participants made mention of funeral plans and grave plots and only one had secured plans for both. One participant reported not implementing any end-of-life care planning but stated this his wife was aware of his wishes, aligning with research which purports that in African American families planning is expressed verbally.

Most striking and demonstrative of current research, were internal caregiver demographics. All participants (n=7) had assigned Power of Attorney (POA) and most (n=6) were female family members. Nearly half (n=3) were daughters, one was a wife and one was a sister. The remaining POA was a “God child” whose gender was not identified.

Confronting Mistrust at End-of-Life

All (n=7) of the participants in this study indicated that hospice workers did not verbally address mistrust or race issues and appeared to be considering these issues for the first time when questioned during the interview. Congruently, most of the participants (n=5) said that they did not have any concerns regarding race and culture that they wanted addressed. One of the participants did not answer the question and one participant expressed, “Well, being black, I guess that’s what I assess. They seem to pay the most [attention] to the Caucasian race for hospice care than for us. And we need it too. We’re sick. We’re sick so we need it too.”

Still, 43% (n=3) of participants said that they entered hospice with a sense of mistrust, which Participant 1 preferred to label as ‘skepticism’. 43% (n=3) of participants also stated that they had no reason to be mistrustful “yet” or felt that they had not been in hospice long enough to make an “assessment”, indicating that they were attune to the nature of their relationship with workers. One participant responded by stating that she does not trust “anybody”. 29% (n=2) of respondents referred to an innate ability to “see through people” and identify their trustworthiness. As evidenced in this excerpt from Participant 1, which was delivered humorously, even “compassion” was viewed suspiciously at first:

I was a little skeptical when I first got there because they were so nice and compassionate and I wasn’t used to that type of treatment so I was like well, there might be something wrong here. There’s an underlying motive here.

Most of the participants (n=5) felt that their race did not affect their care. One participant said that race affected her care but then stated, “I guess that’s right. Cause I guess I answered that right,” indicating that she may have thought this researcher was in search of a particular response. The remaining participant did not answer. Similarly, all of the participants also felt that the race of their hospice workers did not affect their care.

However, more than half of the participants (n=4) made references to historical injustice. In hypothesizing about the hospice owner’s motivation Participant 1 said, “...black people were having such a hard time getting into any place, with any type of extensive care and they needed one. And she put one right over there in the ghetto. Right where it needs to be.” In discussing the lack of African American hospice patients, Participant 3 also made connections to lack of health care in general, “...a lot of African Americans don’t know about hospice. It’s a lot of um don’t even get medical care because of that...” Participant 6’s caregiver also spoke to the need to

increase outreach to reduce caregiver burden saying, “Maybe more African Americans should find out about it [hospice] and participate so there won’t be such a big stress on the family members to know that they got somebody else that can help them.”

Trust Building in the Patient-Worker Relationship at End-of-Life

100% (n=7) of respondents stated that they felt comfortable with their hospice workers. So while hospice workers did not verbally address issues of mistrust, they appeared to address mistrust behaviorally. Based on the researcher’s site, compassion, attentiveness, spiritual respect and inclusion, patient and family engagement, openness and depth of communication all led to a positive experience. It appears that when these variables were met, the respondents in this study felt a sense of “trust” that led them to open up to their hospice workers as articulated by

Participant 5:

...they really make sure that I’m comfortable for the time that I have left. And you can’t really put no scale on that. It’s how each one of them feel within their heart. And so far it seems like it’s not just a job. It’s a heart. That’s what makes me feel so very well.

Compassion was experienced as an intangible quality that involved the smooth execution of logistics as well as a deep expression of care and concern for patient well-being. In explaining her choice to stay at the hospice’s inpatient unit longer than anticipated, Participant 7 furthered stated, “Well, everybody was so kind and so concerned about my comfort and my welfare that I said, well here’s somebody that’s caring about me.”

43% (n=3) of respondents spoke of the hospice workers’ ability to anticipate their needs and meet their demands big or small, as evidenced by excerpts from several respondents.

Participant 1 stated, “They make you feel as comfortable as they possibly can and if you need somebody to talk to, they sit down and talk to you. Whatever needs to be done, they’ll do.”

Participant 5: Well, they make sure that...I'm really comfortable. Make sure I get my medication on time. They make sure that...I have nourishment three times a day. And they also ask if I have any pain and if I'm comfortable. Any wishes that I desire at that particular time, they try to make that possible at that particular time.

Participant 7: They're at your beckon call and it's not a long time waiting for whatever that they do for you. That's what they do. The little girl just braided my hair up. She didn't have to do this...Just whatever it takes to make you comfortable and happy, they're willing to do it, it seems.

Most participants (n=6) reported comfort with asking their hospice workers questions and one participant did not speak to this issue. Additionally, 29% of respondents (n=2) talked about the importance of feeling like they were never being "evaded" as articulated by Participant 4:

Nowadays it's, it's really hard for people to somewhat be honest, and straight forward and since I was raised in a family like, I'll go to my mother with anything...coming up like that...I see and understand a lot why do things go on now. Sometimes people don't know how to be honest and nothing else.

Participant 8 also expressed the importance of mutual respect in her care, "Well for me, because all of my caregivers, they treat me like somebody. They don't be fussing or hollering at me or nothing like that. And what they tell me to do, I do it." Participant 4 extrapolated on this by identifying the hospice workers' ability to honor their end-of-life belief system:

They just let me know about things that would be available, what I would like...And they were real gentle too as far as, you don't have to talk to us about it. You can. And my wife was included. You know, just general things. At the end my, you know when the near is

there, what kind of decision would I like to make so on and so on. And once again, it feels comfortable because I'm open with them. Cause they make me feel like that.

An equal number (n=2) of patients in this study wanted to talk more about death and some did not want to talk about death at all. 29% (n=2) of participants expressed acceptance that their life was reaching its end and nearly half of the participants (n=3) reported improvement in health and an enthusiasm for life.

86% (n=6) of participants said that a family member had participated in their end-of-life decision-making and that hospice had included those family members in their care. The remaining participant stated that he had expected family to be important but because they had not prioritized his care, this was no longer the case. Two participants specifically articulated how staff and family caregivers worked together as a team to support patients and one stated:

You got to have somebody to support. Because I'm telling you, I thought I wasn't going to make it. And see I had help with my grandchildren and with Dr. X and she's a big part of this, getting well and stuff like I am now.

For some patients this team also included God or a higher power. 100% (n=7) of participants indicated that spirituality was an important aspect of the care received in hospice. 57% (n=4) expressed a belief that their life and death was in God's hands. 57% (n=4) specifically identified interactions with the Chaplain as the spiritual care provided, while 43% (n=3) felt spiritually supported by the hospice team at large. Further 43% (n=3) of participants specifically reported that hospice providers inspired them to live or supported their desire for improved health as evidenced in the following excerpt from Participant 1:

...they all are spiritual advisors so to speak. You know spiritually Ms. X and her crew, they always have something spiritual to say about holding on an extra day and maybe there's a better plan, so being a firm believe in the supreme being, I believe it.

Participant 8, a hospice patient of five years, furthered stated, "...I had gave up on myself. But after talking to Dr. X it gave me a point to want to live and that's what I wanted to do and I'm still here."

Hospice Professional Most Associated with Comfort

At this hospice research site, the hospice co-owner is also an oncologist who serves many of the patients in that capacity. Most respondents (n=5) identified the doctor/oncologist as an important player in their care as evidenced by the following excerpt from Participant 1 who was granted a "Compassionate Release" from prison with her efforts:

Well I was a patient of Dr. X's because I had lung cancer. And she pretty much lead me through the process and realizing that I didn't have no back up plan or anything of that sort. She did what she needed to do to get it approved for me to go to the hospice. And so I heard about it through Dr. X.

Four of these five respondents, 57% also identified their nurse as an important figure in their care as articulated by Participant 8, "Simply cause she sees about me. She makes sure I'm alright. She don't just wait to time to come see about me. She gonna call on the phone, wants to know if I'm alright."

43% (n=3) of participants felt that the whole team was important to them, one of which also mentioned the doctor and the nurse specifically, as reported by Participant 5, "Each and every one of them have worked with me here just like family and I accept them just like family."

And the strength and willpower not to give up. To keep on going.” 100% (n=7) of participants also felt that the race of their hospice workers had no affect on the care that they received.

Hospice Professional Best Suited for Outreach

43% (n=3) of participants indicated that they knew someone in hospice prior to their enrollment. 57% (n=4) mentioned that their doctor/oncologist was primary in their decision to go into hospice care as articulated by Participant 8, “I heard of it because they was using it with my aunt...and I got a little involved in taking care of my aunt. But the real way I just got in was with Dr. X.” In this context the doctor was involved with most patients care both as a hospice doctor and as an oncologist. This suggests that their influence may lie not only in their expertise but in their role prior to hospice enrollment.

Summary

This chapter presented and summarized the findings of seven interviews with both African American male and female hospice patients aged 18 years of age and older and receiving services from a hospice program’s in and out patient units. Participants were asked a series of 10 questions, in addition to probe questions where relevant. These questions were designed to gain the perspectives of African Americans on their experience of hospice and the ways in which historical injustice and racial bias may or may not influence those perspectives. Some questions directly addressed racism and historical injustice while others spoke to the cultural preferences among African Americans at end-of-life as identified in previous research. Questions were structured this way in order to locate where the culture of hospice and African Americans are aligned and discordant and to illuminate prejudices which are both overt and insidious. In the following chapter, these findings will be connected to previously reviewed literature and implications for hospice care delivery and outreach and social work practice will be determined.

CHAPTER V

Discussion

The purpose of this qualitative study was to explore African Americans' perspectives on hospice care in order to determine the influence of race-based historical injustice on end-of-life and the necessity of addressing it in expanding access to hospice care. The cultures of both hospice and African Americans and the factors most connected with trust and comfort were explored through narratives of seven African Americans who were enrolled in hospice at the time of the interview. This chapter reviews the findings in the following order: 1) key findings, 2) limitations, 3) implications & recommendations for future research and 4) conclusion.

Key Findings

While the central question in this study centered on the influence of historical injustice at end-of-life among African Americans, interview questions both directly and indirectly addressed this issue in order to capture both overt and insidious forms of oppression. Information was collected from the study participants through questions pertaining to both race and also the factors determined to be culturally appropriate at end-of-life among African Americans. In this way, although mistrust and family framework were of central importance to the research, they could not be explored without also considering the full constellation of factors that are significant to African Americans at end-of-life as supported by Mazanec et al. (2010).

While many studies have interviewed African Americans, this study has become one of few that shares the voices of African American *hospice patients*: people who are not just

considering hospice theoretically but are experiencing it in real time. Participants were asked about end-of-life planning, family, spirituality, mistrust, race, values and beliefs surrounding death and dying and comfort. As participants were being engaged as collaborators in the process of expanding access to hospice care, they were also asked directly how hospice could make itself more accessible to the African American community.

The key findings obtained in this study support the literature but expand on it, by demonstrating how to engage African Americans. In this context, the barriers to hospice care determined by the literature were points of opportunity; participants were joined in their worldview and were therefore trusting of the care provided. In contrast to much of the previously recorded research, the perspectives gained through this study were from satisfied customers, people who were happy with their hospice experience and who spoke with affection and gratitude about the care provided. While the literature review sought to demonstrate the importance of expanding hospice care by identifying flaws within the system of hospice care, the research interviews demonstrated the importance of hospice care by illuminating the depth of comfort it provided the seven participants in this study. Although this study is limited by the small sample size, the fact that 100% of participants were grateful for the care provided underscores the necessity of expanding hospice care beyond the dominant culture. No longer can researchers say that African Americans are culturally adverse to hospice care. The question is not what makes African Americans adverse to hospice, but what makes African Americans interested in hospice care. An expansion initiative of this nature is mutually vulnerable and enacts the vision of culture competence put forth by Kumaş-Tan et al. (2007):

...one of culturally diverse health professionals serving culturally diverse patients, sharing their knowledge while learning from and with patients, and bravely

acknowledging, recognizing, and challenging the many forms of oppression that produce the enormous disparities in health and well-being we witness today” (p. 555).

Addressing Mistrust at End-of-Life

In contrast to the original hypothesis, this study suggests that verbally addressing race-based historical injustice is not a necessary part of end-of-life care among African Americans. All participants had a positive perception of hospice even though these issues had not been addressed and 71% of participants did not have any further questions in this area. 71% of participants also did not feel that their race had anything to do with the care received and all participants agreed that the race of their hospice workers had no bearing on their comfort.

However, when question were less explicitly connected with race contrasting findings were revealed. Half of the participants reported entering hospice with a sense of mistrust and half indicated that while experiences so far had been positive, they were on guard should treatment change. Additionally, when racism was considered in terms of hospice care, 57% of participants easily identified barriers like geographic access, lack of sufficient health care for African Americans in general, lack of awareness of hospice and need for outreach. Insufficient services for African Americans appears to be an accepted fact of life as evidenced in this excerpt from Participant 1:

I know I wanted to be in a place that wasn't all black, I knew that. Because the services in those facilities are usually some of the worst in the state so you need to try to get where you got a mixture of culture in there.

While the research of Reese et al. (1999), Bullock et al. (2006) and Waters (2001) reported on African Americans who explicitly voiced concerns regarding race and historical injustice at end-of-life, participants in this study seemed to illuminate the more insidious impacts

of racism. Within their accounts of how they related to hospice workers they either alluded to or explicitly identified a way of seeing beyond the surface to the truth of a person. bell hooks (1990) articulates how this is both a bi-product of the experience of being an other and an essential aspect of resilience:

Living as we did-on the edge-we developed a particular way of seeing reality. We looked from the outside in and from the inside out. We focused our attention on the center as well as on the margin. We understood both. This mode of seeing reminded us of the existence of a whole universe, a main body made up of both margin and center. Our survival depended on an ongoing public awareness of the separation between margin and center and an ongoing private acknowledgement that we were a necessary, vital part of the whole (p. 341).

In hospice care, prior experiences of discrimination and this awareness of difference sometimes translates into a vigilant need to protect. Cort (2004) discusses how what some researchers may perceive as a barrier to hospice care may be a coping strategy for survival in a hostile world. Likewise, Bullock et al. (2006) and Johnson et al. (2005) point to the importance of survival in the African American community and the ways in which hospice appears to be the opposite. Interestingly, some participants in this study saw hospice as a source of hope and one specifically said that she had to accept hospice care in order to “survive”. So when framed appropriately, hospice became a part of the survival story as opposed to a threat to it. The need to preserve hope at end-of-life is an important factor to consider when working with African Americans and it is also an essential piece of survival for most people who face end-of-life.

While mistrust was not addressed verbally at this hospice, many of the barriers to hospice care identified by research appeared to be addressed in practice. More central to this study than factors contributing to mistrust, were factors contributing to trust.

Trust Factors at End-of-Life

All of the participants in this study said they were comfortable with their hospice workers regardless of race. The words used to describe the hospice workers were notably rich: “compassionate, friendly, trusting, gentle, humble, nice, giving, thoughtful, respectful and familial.” The deep way of seeing described above, appeared to allow for very full connection when a situation or person was determined to be trusting, as they were at this site.

Hospice workers were perceived as experiencing their work as a vocation and not as a job. They were thought to truly care for patients, to go above and beyond, to anticipate needs, meet any demand and to be non-evasive. These behaviors directly address the fears outlined in the literature of being treated like a guinea pig, being left to die, denied services and not having end-of-life wishes honored. So when dealing with a population who has endured centuries of maltreatment, these are important qualities of care to deliver and at the same time they are appealing to human beings universally. Interviews with the research participants revealed that there is not a magic bit of knowledge that workers must have in order to successfully care for African Americans, but rather that their success lies in delivering care that is high quality and sincere.

Congruently, when this quality of care is delivered, it becomes impossible to perceive hospice as a form of deprivation or to experience it exclusively as “doing nothing”. It is clear that care is being provided and that this care is relieving if not essential at end-of-life.

Family

Supporting the literature, all but one participant in this study stated that a family member had been part of their decision-making and that hospice had included them in their care. In congruence with the research of Born et al. (2004), which states that caretaking is the role of the children and spouse, half of the family caregivers were daughters, one was a spouse and one was a sister. Additionally, nearly all of the caregivers were female suggesting a need to include African American women in hospice outreach efforts and decision-making. Mazanec et al. (2010) identified the importance of an extended kinship network among African Americans but most of the caregivers in this study were within the nuclear family.

Supporting the research of Born et al. (2004), Braun et al. (2008) and Washington et al. (2008), one caregiver spoke to the importance of expanding hospice outreach to African Americans in order to relieve caregiver burnout. She expressed an enthusiasm for hospice, saying that she would become an “advocate.” Further illuminating the need for hospice accessibility among all people, another caregiver also stated that her brother was put into hospice because he needed “round the clock care,” which is difficult for any family of any race to provide regardless of their belief systems.

Two hospice patients used words like “family” and “home” to describe hospice care, which also spoke to the depth of relationship between patients and workers. As evidenced by one participant whose family was not involved in care, this may be especially important to those African Americans who do not have family support at end-of-life. Another participant spoke to a desire to die where she was living, despite the fact that she had family caregivers available somewhere else, which may be a common theme among hospice patients.

While family inclusion in hospice care was important, in terms of research techniques, only two participants chose to include a family member in their interview. There were however, two additional patients who were interested in interviewing but did not because their family member could not be present.

Spirituality and Beliefs around Death and Dying

Supporting the literature, for participants in this study, death and spirituality appeared to be strongly correlated and the ease with which all members of the hospice team spoke in spiritual terms was appreciated. All of the participants in this study indicated that spirituality was an important aspect of the care received in hospice and 57% indicated that their death was in God's hands as supported by Johnson et al. (2005). Supporting Bullock et al. (2006), for nearly half of the patients this included a hope that health would improve, which was validated and supported by hospice staff at this site. Two of these patients had actually seen improved health and had been enrolled in hospice for more than one year. Two patients who both did and did not openly accept their death, spoke to how their life had been "measured by God" or that it was no longer in "man's hands". While two other patients expressed a desire to talk more about God and their health. Another patient who was initially very resistant to hospice, attributed her ability to survive to God and her belief in God to her survival. In all cases, it appeared that the hospice staff honored the worldview of the patient and that verbal acknowledgement of death was not a necessary component of participating in hospice care. In this space, the tension between hospice and sustaining life seemed to disappear and an understanding that people hold end-of-life differently was demonstrated and respected.

While Kagawa-Singer & Blackhall (2001) spoke of an African American ethic around struggle and sustaining pain, nearly half of the participants spoke of the value of physical

comfort. In fact, the perception that hospice workers were compassionate seemed very linked to their ability to sustain comfort physically, emotionally and spiritually. Almost all of the patients seemed struck by how comprehensive their care was. It was the family, working with the doctors who worked with the hospice staff that led to a sense of being truly cared for and about. Again, this may be specifically important to African Americans because it contrasts the typical experience with the health care system, but these are also qualities of care that are universally desirable.

Hospice Professional Most Associated with Comfort

The doctor was the most prominent figure in hospice care for 71% of these patients, which demonstrates the importance of their role in end-of-life decision-making. The oncologist, who was also co-owner of the hospice, was often spoken of in heroic terms and seemed to have rescued people from insurmountable situations. One patient was granted a Compassionate Release from prison at the doctor's hands, another described being wrapped in blankets and sent to hospice when she thought there were no alternatives and another person's hospice resistance was transformed by the information and attentiveness provided by the doctor.

As the African American doctors studied by Braun et al. (2010) were natural translators between hospice and African American culture, so too was this doctor an organic conduit between the hospital and hospice care. As a hospice owner, one can assume the oncologist has a knowledge of and belief in hospice that allows for comfortably presenting hospice as an option for terminally ill patients. Likewise, the doctor was experienced as someone who was invested in caring for African American people as eluded to by one participant who referenced the geographic location of the hospice. Contrary to Cort's (2004) assertion that family members most influenced African American decision-making, and although two patients had heard of

hospice through family members or friends, most maintained that the doctor was most responsible for their enrollment.

57% of patients mentioned the nurse, making her the second most integral to participants' sense of comfort. The nurse is on the front lines, providing care from the trenches and addressing patients' physical and emotional needs making her a likely candidate for this association. 43% of patients also mentioned the hospice team as a whole. The workers at this hospice were multi-cultural and all participants felt that their race was not important. At this hospice site it is clear that cultural competency is systemic, embodied individually and structurally and from management to staff. The fact that these workers live in a place with a strong and large African American population and that they have chosen to work at a hospice in an African American neighborhood may speak to a natural cultural competence, which may not be indicative of the average hospice setting.

In contrast to the original hypothesis set forth by this researcher, social workers were not specifically mentioned as a professional associated with comfort in hospice care. Because the philosophy and skills of social workers are so congruent with the goals of culturally competent end-of-life care, there is then an opportunity for social workers to determine how to broaden their role in this setting. The social workers current lack of impact may be due to several factors including the limited time hospice social workers spend with patients as compared to the doctor or nurse and the limitations of their role in the hospice setting. It is possible that increasing time spent and redefining social workers' purpose on the hospice team would increase their importance. It is also possible that the social worker's role in expanding access to hospice care among African Americans will be advisory – about planning curriculum and programs as opposed to implementing them.

Primary Informants

In this study, the doctor's dual role as oncologist and hospice owner, played a pivotal part in creating an access way to hospice. Not only was the doctor the professional most associated with comfort but the doctor also influenced end-of-life decision-making more than family and community members. A sense of trust was already created between doctor and patient, which naturally transferred into the hospice setting. Hospice was viewed as a medical option when there were no other options, as a way to get care when there were no funds and as a place where comfort would be provided. In this context, hospice was experienced more as hope than giving up and this appears to be a direct result of the patients' experience of the doctor as a hero.

As reflected in much of the research, it is not the experience of hospice itself, but the end-of-life decision-making that takes place prior to hospice that determines enrollment. 29% of participants spoke of the importance of seeing hospices in their own neighborhoods; 29% expressed the need for individuals to know that hospice is potentially cost free; and 57% stressed the need for outreach, even expressing a willingness to become advocates. In congruence with the literature, increasing access to hospice care is not only about who presents the information but how it is presented.

Limitations

The major limitation of this study is the sample size (n=7). While the study participants reflected the larger population in terms of age and gender, generalizability is limited because the insights gathered were from a small sample size. Likewise, data was collected at one hospice site with very specific barrier reducing qualities, which are not reflective of the average hospice today. The owner's dual role as doctor and the fact that they were a person of color, geographic location of the hospice and the diversity of the hospice workers and patients all contributed to the

elimination of several major barriers. So while 100% of participants in this study experienced hospice positively, it cannot be said that hospice care would be experienced positively in the more average setting.

Moreover, due to the small sample size and based on previous research by Reese et al. (1999), Bullock et al. (2006) and Waters (2001), it cannot be assumed that all African Americans do not need to verbally address race-based historical injustice at end-of-life. Further research might specifically target individuals who are making these types of considerations at end-of-life to gain deeper insight into proper interventions.

Due to the limited research period and vulnerability of this population, only eight hospice patients were interviewed, one of which withdrew from the study. While additional patients were recruited, due to limited cognition or lack of caregiver presence, they were not able to participate. This researcher also attempted to work with another hospice program that had a formal cultural competency plan in place but they were already working with a student on a similar project and felt that participation would be limited.

Due to safety concerns, the Internal Review Board prohibited this researcher from conducting in home interviews without the presence of a hospice staff member. Because 80% of hospice patients at this provider receive care in their own homes and the experience of in and out patient hospice are different, it was necessary to include both perspectives. There is no doubt however, that the hospice staff person influenced the interviews. The presence of the staff member may have lent this researcher some credibility, which allowed participants to be more open and at the same time it is possible that the staff member limited patients' ability to speak openly. Still, the staff member was present for only 43% of the interviews (n=3) and patients had the option of excluding them from the interview room itself.

Additionally, recruiting participants and orienting them to the interview process, required sharing the research question. The disparity in hospice usage among race and a belief that it is related to racism was inherent in the central question for this study, which then automatically frames the experience in racial terms when it may not have been experienced that way before. Many participants informally reported that they did not know hospice was more widely used among whites and as described, one participant clearly stated that she wanted to say what was “right.”

It was also difficult to launch into topics as deeply personal and emotionally loaded as racism and death, without any prior contact. This study hinges on the importance of trust building between the African American community and health care professionals and the research method did not allow much space for trust building to take place between researcher and participant. Additionally, the race of this researcher may have limited the responses of participants. But most participants appeared to share their experiences quite openly and as reported, most participants did not attribute their race or the race of their hospice workers to their experience of comfort in hospice.

Implications & Recommendations for future research

The wealth of insight learned from this small group of hospice patients suggests the need for and potential significance of additional studies to explore the variables related to trust and mistrust among African American hospice patients. The relevance of historical injustice on end-of-life decision-making was dominant in the literature but did not appear to be an overt factor among participants in this study. This supports the findings of Armstrong et al. (2008) whose study demonstrated that mistrust was linked to values and not professional competence. At this hospice, where the values were congruent with those of African Americans, trust was developed

and doctors could be relied on for their expertise. Crawley & Payne (2006) spoke of the importance of framing mistrust situationally. The experiences of the participants in this study demonstrate that when the hospice provider does not have barriers against African American patients, African American patients also do not have barriers against hospice.

Likewise, two participants spoke to the importance of being open to receiving information and care. Participant 1 supported the research of Cort (2004) that less trust is correlated with dissatisfaction with care, as evidenced in this excerpt:

Cause you go up there with negative attitudes and everything like I did when I first got there, they would want me to hurry up and get out of there. They couldn't wait till I got outta there. But when I went back after I saw my mama and I saw the look on my mama's face, I told Dr. X, I'm ready. And I'm still here now.

When space for trust building was created, openness to care was also created.

Supporting the research of Kagawa-Singer & Blackhall (2001) who point out the importance of quality care accompanying outreach among African Americans, at this site, where quality care was provided, the number one participant recommendation for increasing hospice care among African Americans was outreach. The person most associated with comfort was also linked with interventions prior to hospice enrollment. This supports the research of Braun et al. (2010), in revealing the importance of hospices partnering with doctors in their outreach efforts.

This study showed that care providers were experienced as a family or network of which the doctor was a key participant and in most cases the ambassador to hospice. The doctor at this site exemplified the recommendations by African American doctors in Braun et al.'s study who identified the importance of redefining hospice as providing comfort care and not doing

“nothing.” Therefore education efforts must not just target potential African American hospice patients but also doctors who are in the position of informing patients of this option.

In contrast to the research, none of the patients in this study reported a desire to pursue life-sustaining treatment. Whether or not this was an issue at the time of decision-making remains unclear. While this study underlines the importance of hospice in the African American community and speaks to what is appreciated about hospice once people are enrolled, it less directly captured the thought process during the time of decision-making. Future research might focus on African Americans who are currently considering hospice. Studies at hospice sites that vary in terms of cultural competence may also provide further insight into how to train hospice workers across levels of cultural competence. Future research might also focus on capturing the processes undertaken by hospices in order to increase cultural competency in end-of-life care.

Conclusion

In his examination of Blackness, Quashie (2009) points to the ways in which "resistance becomes the dominant idiom for reading and describing Black culture" and the limitations this imposes on Black identity (p. 332). He postulates, that in only noticing the resistance of African American people, the complexity of their inner experience is missed. Likewise, in this hospice setting, where staff and patients were diverse, where services were geographically accessible, worldviews were honored and sincere care was provided, participants were relieved of the need to be only resistant and as such they were able to relate to hospice, not just in terms of their blackness but in terms of their humanity.

This study clearly displays that hospice can bring comfort and richness into the lives of African Americans. The experiences of the participants at this hospice demonstrate how what researchers have identified as barriers between hospice care and African Americans can

seamlessly blend together when an openness to difference and a foundation of “trust and care” are created and cultivated. There is both cultural relevance around trust building within this community and trust and comfort are universally appealing qualities of care. Expanding access to hospice care among African Americans is then important not only because it is the premiere end-of-life service but also because it provides an opportunity for African Americans to experience death in a new way, where it is not inextricably linked with bodily violence (Holloway, 2006, Introduction section, para. 1). Researchers who say that race and culture are and are not important at end-of-life are both right. African Americans in hospice must be considered as both individuals with personal beliefs and as a collective with a culturally shared history. Further, when hospices are not defined by a racialized culture, than hospice patients are also less racialized.

Making hospice more accessible to African Americans and people of all social identities is a complex undertaking that requires micro and macro level changes. While policy level changes to the stipulations of the Medicare Benefit would likely increase hospice use among African Americans, this study shows that hospice was not experienced in opposition to beliefs around sustaining life. African Americans at this site were able to sustain their belief in life and God’s jurisdiction over death and to understand hospice as an element of survival and these views were supported and validated by hospice workers. Hospice enrollment requires a prognosis of six months or less but it does not stipulate how people hold that information. When spiritual values of all kinds were honored, hospice could be the source of comfort it was created to be.

The significant role that physicians have in the lives of terminally ill patients was also confirmed. At this site, it was the physician that played the most important role in patient

knowledge about hospice, placement in hospice and acceptance of the care provided. The discomfort many physicians show with discussing end-of-life can then become particularly harmful to African Americans who have lesser awareness of hospice in the first place. This tells us that physicians need to take a more assertive role in sharing options with terminally ill patients, and in informing patients of hospice as a viable option; and that hospices must take an assertive role in educating physicians on hospice care.

This study also demonstrates the need for hospice programs to be available and visible within African American communities in order for it to be received as a valuable resource. Incorporating hospices into the fabric of the community will allow African Americans to more fully understand the services and mission of hospice while reducing fear and stigma. Local hospices also allow African Americans to transition within familiar environments and surroundings, if not at home. This is an important need, not just for many African Americans, but for many individuals who do not want to die alone away from their family, friends and familiar surroundings. It also is probable, that when placed within the community, hospices will attract employees from the community or workers who are interested in serving this community, which inherently expands diversity and cultural competence.

It also appears that many African Americans in this study were not fully aware of their eligibility for hospice programs, as they perceived it to come at a cost. This appears to be a misnomer within the African American community and may indeed be a significant factor for why African Americans shy away from hospice programs. If this is the case, then more public understanding about hospice eligibility and cost requirements are necessary within African American communities.

With the aging population and diversity rapidly increasing in America, it is important to create opportunities for all Americans to die a “good death,” as defined personally and culturally. This study offers many insights for hospice programs and workers who are willing to take on the necessary and courageous work of creating multicultural services that are not only accessible to people of all social identities but which interrupt patterns of oppression. The lack of association between comfort and social workers among the African Americans in this study reveals a point of opportunity for the social work profession. The mission of social work and training of social workers make us natural leaders in increasing the value of diversity in hospice and developing the policies and procedures for delivering culturally competent care.

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APPENDIX A

HSR APPROVAL LETTER



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

February 16, 2012

Nikki Bagli

Dear Nikki,

Your revisions are accepted. Nice job on the questions and elsewhere! You are approved.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your research.

Sincerely,

A handwritten signature in black ink, appearing to read 'David L. Burton', with a long horizontal flourish extending to the right.

David L. Burton, M.S.W., Ph.D.
Chair, Human Subjects Review Committee

CC: Narviar Barker, Research Advisor

APPENDIX B
PATIENT CONSENT FORM

Individual Code # _____ , Family Code # _____,

Date

Dear (Name of Participant),

My name is Nikki Bagli. I am a graduate student at Smith College School for Social Work in Northampton, Massachusetts. I am conducting a study to examine the culture of hospice and to engage African American hospice patients as collaborators in expanding access to hospice care within the African American community. The existing hospice model has been promoted by many health care professionals as an optimal model of care at end-of-life, but according to the National Hospice and Palliative Care Organization in 2009, only 8.7% of hospice patients were African American, and 80.7% were white, with whites using hospice 40% more than African Americans.

This study is designed to explore your perspectives and personal insights on what has and has not been welcoming about the hospice process, with a specific focus on whether race-based historical injustice within the health care system has had an impact on your end-of-life decision-making and experience and if it has, how that was managed by hospice workers. Study participants must be actively enrolled in hospice, African American, English speaking, male or female and 18 years of age or older. Any member/s of your support system that has been part of your decision-making process is invited to join your interview if you wish and will need to sign their own consent form. The data from my interviews will be used for my thesis, which is part of the requirements for the Master of Social Work degree at Smith College School for Social Work,

and possibly for future publications and presentations. By participating in this study, you may contribute to a growing body of knowledge that can help hospice programs better meet the needs of African American individuals and communities during end-of-life.

Nature of Participation

As a participant, you and your support persons (including anyone who you are not employing that is involved in your end-of-life decision-making) will take part in a 60 to 90 minute interview with me. This will take place in the setting of your choosing. First, you and your support persons (if they participate) will sign an informed consent letter. Then, I will ask you and your support persons (if they participate) a list of 10 guided interview questions so that I can better understand what qualities of care are important to you at end-of-life; and how you made your decisions about the services you chose.

Questions in this study are meant to encourage reflection around end-of-life decision-making and are not intended to inform or critique your experience, beliefs or behaviors. Support persons can agree or disagree when you respond to questions and I will do my best to make certain that everyone has a chance to share their viewpoints. If a question arises that you do not feel comfortable answering, you do not have to answer the question. Please note that you may also discontinue participation in the study at any point prior to March 31, 2012, without penalty. Your participation in this study will have no bearing on the quality of care you receive.

Risks

Minimal risk from participation is anticipated. You may experience some distress when reflecting on end-of-life and end-of-life decision-making for yourself or your loved one. You may also be uncomfortable sharing your thoughts about end-of-life and decision-making with

support persons or this researcher. You may also be uncomfortable discussing issues of race or racism with this researcher who is white, or with other interview participants.

██ will follow up with you within 24-hours of the interview to provide an opportunity to discuss any discomfort that may have emerged as a result of the interview and to determine if additional services are needed.

Benefits

There may be significant benefits to participation in this study. You may gain new insight into your end-of-life wishes and expectations, as well as those of your support persons who will be given the opportunity to share and or discuss their perceptions and needs of hospice. Your feedback may contribute to the overall body of knowledge on how to better serve African Americans at end-of-life and how to more effectively engage the African American community in hospice services. This information may also inform future hospice practices and strategies for service, recruitment and policy making. There will be no monetary or other material compensation for participation in this study.

Confidentiality

Your identity will be held in strict confidence. Data will be summarized and all information will be presented in aggregate form. I will protect and maintain confidentiality of what you share with me in your interview. I will use a numerical code and or masked name to identify your data and your name; and your hospice program will not appear on the transcripts, my thesis, its dissemination, or in possible future publications. All quotes and illustrative vignettes will be written in a manner that does not reveal information that could identify you or your support persons. According to federal guidelines, I will keep all of the notes, transcripts, audio-recording, and this informed consent letter in a securely locked location for three years.

The identifying information on this letter will remain separate from your information. Beyond this three-year period, information that I am not actively using will be physically destroyed by me.

Participation in this study is voluntary. You may skip any question. You may withdraw from the interview before, during or after the study begins. You may stop participation in the interview at any point prior to March 31, 2012. You will not be penalized in any way if you withdrawal from the study. If you wish to withdraw, either before, during, or after the interview, you may either notify me in person or contact me by letter, email, or phone. At that point I will immediately destroy all materials relating to you, if received prior to March 31, 2012. You will not be penalized in any way if you decide to withdraw from this study.

If you have any concerns about this study, you may speak with me, or you may contact the Chair of the Human Subject Review Committee at the Smith College School for Social Work at 413.585.7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTOOD THE ABOVE INFORMATION, THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS, AND THAT YOU AGREE TO PARTICIPATE IN THIS STUDY.

Signature of Participant: _____ Date _____

Signature of Researcher: _____ Date _____

Please contact me at anytime if you have any questions about this study. Thank you for so generously participating in this study and putting your time and energy toward my research efforts.

Sincerely,

Nikki Bagli
MSW Candidate '12

APPENDIX C

SUPPORT PERSON CONSENT FORM

Individual Code # _____ , Family Code # _____,

Date

Dear (Name of Participant),

My name is Nikki Bagli. I am a graduate student at Smith College School for Social Work in Northampton, Massachusetts. I am conducting a study to examine the culture of hospice and to engage African American hospice patients as collaborators in expanding access to hospice care within the African American community. The existing hospice model has been promoted by many health care professionals as an optimal model of care at end-of-life, but according to the National Hospice and Palliative Care Organization in 2009, only 8.7% of hospice patients were African American, and 80.7% were white, with whites using hospice 40% more than African Americans.

This study is designed to explore your perspectives and personal insights on what has and has not been welcoming about the hospice process, with a specific focus on whether race-based historical injustice within the health care system has had an impact on your end-of-life decision-making and experience and if it has, how that was managed by hospice workers. Study participants must be actively enrolled in hospice, African American, English speaking, male or female and 18 years of age or older. As a support person to a hospice patient fitting this criteria, you have been invited to join this interview. The data from my interviews will be used for my thesis, which is part of the requirements for the Master of Social Work degree at Smith College School for Social Work, and possibly for future publications and presentations. By participating

in this study, you may contribute to a growing body of knowledge that can help hospice programs better meet the needs of African American individuals and communities during end-of-life.

Nature of Participation

You and the person whose care you are involved in will take part in a 60 to 90 minute interview with me. This will take place in the setting of the hospice patient's choosing. First, you and the person whose care you are involved in will sign an informed consent letter. Then, I will ask you and the person whose care you are involved in a list of 10 guided interview questions so that I can better understand what qualities of care are important to you at end-of-life; and how your loved one made decisions about the services they chose.

Questions in this study are meant to encourage reflection around end-of-life decision-making and are not intended to inform or critique your experience, beliefs or behaviors. You can agree or disagree with the person whose care you are involved in when you respond to questions and I will do my best to make certain that everyone has a chance to share their viewpoints. If a question arises that you do not feel comfortable answering, you do not have to answer the question. Please note that you may also discontinue participation in the study at any point prior to March 31, 2012, without penalty. Your participation in this study will have no bearing on the quality of care received by the person whose care you are involved in.

Risks

Minimal risk from participation is anticipated. You may experience some distress when reflecting on end-of-life and end-of-life decision-making for the person whose care you are involved in and your self. You may also be uncomfortable sharing your thoughts about end-of-life and decision-making with the person whose care you are involved in or with this researcher.

You may also be uncomfortable discussing issues of race or racism with this researcher who is white or with other interview participants.

██ will follow up with you within 24-hours of the interview to provide an opportunity to discuss any discomfort that may have emerged as a result of the interview and to determine if additional services are needed.

Benefits

There may be significant benefits to participation in this study. You may gain new insight into the end-of-life wishes and expectations of the person whose care you are involved in, as well as your own since you will be given the opportunity to share and or discuss your perceptions and needs of hospice. Your feedback may contribute to the overall body of knowledge on how to better serve African Americans at end-of-life and how to more effectively engage the African American community in hospice services. This information may also inform future hospice practices and strategies for service, recruitment and policy making. There will be no monetary or other material compensation for participation in this study.

Confidentiality

Your identity will be held in strict confidence. Data will be summarized and all information will be presented in aggregate form. I will protect and maintain confidentiality of what you share with me in your interview. I will use a numerical code and or masked name to identify your data and your name; and your hospice program will not appear on the transcripts, my thesis, its dissemination, or in possible future publications. All quotes and illustrative vignettes will be written in a manner that does not reveal information that could identify you or your support persons. According to federal guidelines, I will keep all of the notes, transcripts, audio-recording, and this informed consent letter in a securely locked location for three years.

The identifying information on this letter will remain separate from your information. Beyond this three-year period, information that I am not actively using will be physically destroyed by me.

Participation in this study is voluntary. You may skip any question. You may withdraw from the interview before, during or after the study begins. You may stop participation in the interview at any point prior to March 31, 2012; however if you are not the hospice patient, it is not possible to withdraw data pertaining to you from the audio-recording up to the point that you depart. Your responses and those of the person whose care you are involved in will be connected by the flow of the conversation and difficult to separate. You will not be penalized in any way if you withdrawal from the study. If you wish to withdraw, either before, during, or after the interview, you may either notify me in person or contact me by letter, email, or phone. At that point I will immediately destroy all materials relating to you, if received prior to March 31, 2012. You will not be penalized in any way if you decide to withdraw from this study.

If you have any concerns about this study, you may speak with me, or you may contact the Chair of the Human Subject Review Committee at the Smith College School for Social Work at 413.585.7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTOOD THE ABOVE INFORMATION, THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS, AND THAT YOU AGREE TO PARTICIPATE IN THIS STUDY.

Signature of Participant/Support Person: _____ Date _____

Signature of Researcher: _____ Date _____

Please contact me at anytime if you have any questions about this study. Thank you for so generously participating in this study and putting your time and energy toward my research efforts.

Sincerely,

Nikki Bagli
MSW Candidate '12

APPENDIX D

INTERVIEW GUIDE

Demographics of hospice patient

Hospice Patient and Hospice Support Person/s:
Relationship/s of Support Person to Hospice Patient:
Occupation of Support Person/s:
Patient Age:
Patient Gender:
Current Length of Hospice Stay (of self or loved one):
Highest Level of Education Completed:
Marital Status:
Current Residence:

Interview Questions

1. How did you hear about hospice and what led to your decision to use it?
2. What type of end-of-life care planning have you done?
 - a. Advanced care directive?
 - b. Allow Natural Death (AND) or Do Not Resuscitate (DNR)?
 - c. Living will?
 - d. Power of Attorney?
3. Has a family member, friend or non-paid support person been involved in your end-of-life decision-making and care? Have the hospice workers included them in your care? If so, how? Is this important to you?
4. Has spirituality or religion been a part of the care provided by hospice? If so, how? Is this important to you?
5. What, if anything, did you dislike about the healthcare system and/or hospice? Was mistrust an issue for you? If so, please explain.
 - a. Did you feel comfortable asking questions? How was this handled by hospice workers?
6. Do you think your race affects the care that you receive? If yes, in what way? Would you have liked your concerns around race and culture to be specifically addressed? How might this have affected your experience in hospice?
7. Were your values and/or beliefs about death listened to and accepted by hospice workers in your advance care planning/end-of-life decision-making? Please give me an example of how this was done.
 - a. Could anything have been done differently? If so, what?

8. Are you comfortable with your hospice workers?
 - a. What about your hospice workers makes you comfortable or uncomfortable?
 - b. Does their race have any affect on your comfort?
 - c. Which member of your hospice team, if any, had the greatest affect on your level of comfort or acceptance of your end-of-life decision-making?
9. How can hospice make itself more accessible to you and other African Americans?
10. Is there anything that you would like to share with me that I have not already asked?

Thank you for your participation in my research.

APPENDIX E
RESEARCH FLIER

AFRICAN AMERICAN HOSPICE PATIENTS NEEDED FOR A STUDY

WHO

Actively enrolled hospice patients who are African American, aged 18 or older and are English speaking.

WHY

This research is being done to examine the experiences of African Americans receiving end-of-life care from Hospice providers, and to engage African American hospice patients as collaborators in expanding access to hospice care within the African American community.

BENEFITS AND RISKS

The benefits to participation in this study are that you may contribute to current research on hospice services and outreach to the African American community. Providing insight and giving voice to the needs of African American hospice patients may be invaluable to professional service providers, educators, administrators, and policymakers.

There are minimal risks involved in this study. You may experience feelings of discomfort when discussing your emotions, decisions about end-of-life, or personal reflections. Members of the hospice team will follow-up with you within 24-hours of the interview for support, if needed. There will be no monetary compensation for your participation.

WHEN AND WHERE

Interviews will be 60 to 90 minutes and will take place in a location of your choosing. You are invited to include any member/s of your support system who have been part of your end-of-life decision-making process and care in the interview.

HOW

If you or anyone you know might be interested in participating, please contact Nikki Bagli for more information or see [REDACTED]
[REDACTED]

Contact Information:

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