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African Americans and Hospice:
A Culture-Centered Exploration of Disparities in End-of-Life Care

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
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Abstract

As the United States' population ages and grows more diverse, scholars and practitioners have grown increasingly concerned about persistent disparities in the cost and quality of end-of-life health care, particularly with regard to African Americans. Although a variety of factors may influence these disparities, most scholars agree that the underutilization of hospice care by this population is an important contributor. Drawing from the culture-centered approach to health communication and narrative theory, the present study explores African American patients and caregivers' experiences with hospice care and takes an initial step toward addressing disparities in end-of-life care. I begin this study, first, by positioning it within existing literature on health disparities and the underutilization of hospice care. I then outline the study's context and the ethnographic methods I used to complete it. Next, I discuss (a) participants' understanding of disparities in hospice utilization, (b) how participants' narrate their decisions about and experiences with hospice care, and (c) co-constructed solutions for addressing disparities in end-of-life care by creating partnerships between community members and local hospice organizations.

Introduction

Are certain forms of discrimination demonstrably more noxious than others?...[Scholars] who take these as research questions study both individual experience and the larger social matrix in which it is embedded in order to see how various large-scale social forces come to be translated into personal distress and disease. By what mechanisms do social forces ranging from poverty to racism become embodied as individual experience?”(Farmer, 1996, pp. 261-262)

Despite compelling DNA evidence that all humans are one biological species (American Association of Physical Anthropology, 1996), the social conception of race is a powerful ideological and institutional marker in contemporary American society (Allen, 2007; Giroux, 2006; Jenkins & Dillon, 2012; Proudford & Nkomo, 2006). As Wilkinson (1995) argues, “race remains a principal determinant of social organization, affecting every aspect of employment, educational opportunity, health, and justice” (p. 168). The continued eminence of race in social organizing has also perpetuated historical racial discrimination and inequality, as evidenced by continued disparities in income levels (Attewell, Kasinitz, & Dunn, 2010), educational achievement (Cruz & Duplass, 2009), and incarceration rates (Richmond & Johnson, 2009).

Among the most alarming effects of racial discrimination in the United States are persistent health disparities experienced by African Americans and other racial/ethnic

minorities. A substantial body of evidence indicates that African Americans face significantly more serious health problems, such as higher morbidity and mortality rates, than non-Hispanic white health care consumers (Dutta & Kreps, in press; Kreps, 2006; Thomas, Quinn, Butler, Fryer, & Garza, 2011), often while having limited access to quality medical care (Institute of Medicine (IOM), 2002; Len-Rios, 2012). Health disparities exist across a range of different health conditions and remain even after controlling for differences in income and health insurance (Kreps, 2006; Woolf, Johnson, Fryer, Rust, & Satcher, 2004).

Despite being a national focus of research and health intervention efforts for nearly 30 years, contemporary investigations demonstrate that health disparities persist in morbidity, mortality, and the quality of available health care services (Centers for Disease Control and Prevention (CDC), 2011; IOM, 2002; National Cancer Institute (NCI), 2008; Thomas et al., 2011). African Americans, in particular, continue to bear the greatest burden of health inequality. For example, African Americans experience disproportionate incidences of the most common types of cancer and a cancer death rate that is more than 25% higher than white patients (NCI, 2008). Among other common health conditions, African American men and women are more likely to die from coronary heart disease and stroke than their white counterparts (CDC, 2011). African Americans also experience inequitable rates of infant mortality, diabetes, and HIV/AIDS (CDC, 2010; Keppel, Percy, & Klein, 2004). The continuing magnitude of health inequities suggests that efforts to understand and address disparities must remain a significant priority among researchers, practitioners, and government agencies for the foreseeable future (IOM, 2002; Thomas et al., 2011).

As the United States' population ages and rates of terminal illnesses continue to rise, disparities in the cost and quality of end-of-life care among older African Americans has become an increasing concern for health researchers and practitioners (Dillon, Roscoe, & Jenkins, 2012; Melhado & Bushy, 2011; Melhado & Byers, 2011; United States Census Bureau, 2011). As noted above, African Americans (particularly older adults) experience consistently higher morbidity and mortality rates than any other racial and ethnic group (Satcher & Pamies, 2006; Hargrave, 2010). The care that African American patients receive as they near the end of life, further, is generally more expensive and of lower quality (Hanchate, Kronman, Young-Xu, Ash, Welch, Teno, & Mor, 2005). As Melhado and Bushy (2011) note, the "health needs of African American older adults are the same as those for any other group at the end of life, yet services provided to older African Americans with chronic conditions and comorbidities are less than optimal" (p. 1).

Some, but not all, of the disparities in end-of-life care can be attributed to larger populations of African Americans living in regions with higher overall treatment intensity (i.e., quantity of medical services provided) and spending in the last six months of life (Baicker, Chandra, Skinner, & Wennberg, 2004) and their use of higher intensity hospitals (Barnato, Chang, Saynina, & Garber, 2007). Many scholars argue, however, that disparities in end-of-life care are (at least) partially the result of the underutilization of hospice care by African American patients and their loved ones (Bullock, 2011; Dillon et al., 2012; Enguidanos, Kogan, Lorenz, & Taylor, 2011; Yanchu, Farmer, & Leahman, 2010).

Over the past decade, scholars have focused on understanding why African Americans are less likely to use hospice services and identifying viable methods to increase their participation in hospice programs. In accordance with the dominant approach to health disparities research (Basu, 2010; Dutta, 2008; Dutta, Anaele, & Jones, 2013), the primary focus of these efforts has been extracting cultural traits and decision-making factors in order to develop targeted health campaigns designed to promote hospice care among the African American population (e.g., Bullock, 2011; Enguidanos et al., 2011; Yanchu et al., 2010). Such expert-driven campaigns have been critiqued in recent years by scholars who argue that they are often out of touch with the lived experiences of marginalized populations who are most affected by health inequities (Basu & Dutta, 2008; Dillon & Basu, in press; Dutta, 2008; Dutta et al., 2013). These scholars advocate the inclusion of participants' voices in efforts to make sense of health issues and develop locally meaningful solutions to promote greater health equity (Airhihenbuwa, 2007; Basu & Dutta, 2008, 2009; Dillon & Basu, in press; Dutta, 2007, 2008, 2012).

The culture-centered approach (CCA) responds to the need for participatory, community-driven solutions that address health disparities in marginalized communities by highlighting the dynamic interplay between culture, structure, and agency (Basu & Dutta, 2009; Dillon & Basu, in press; Dutta, 2008). The CCA locates health meanings within active, communicative processes through which individuals make sense of cultural frameworks and institutional structures that influence their ability to enact health (Basu, 2010, Dutta, 2008). Furthermore, the CCA foregrounds the capacity of community members to define salient health problems and co-construct corresponding solutions through dialogic engagement with health communication scholars (Dutta, 2008, 2012;

Dutta & Basu, 2011; Dutta et al., 2013). Drawing on the CCA, this study takes an initial (yet important) step toward understanding disparities in hospice utilization and working toward meaningful solutions to address this issue by engaging with the narrated experiences of African American hospice patients and caregivers.

In the following chapter, “Tracing the Landscape of Disparities in End-of-Life Care among African Americans,” I position this study within existing literature on health disparities and the underutilization of hospice care. I also describe how adopting a culture-centered, narrative approach can address limitations found in the current literature. I end the chapter by offering the four research questions that guided this study. The second chapter is titled “A Culture-Centered Methodology.” Grounded in the tenets of CCA research (Dutta, 2008; Dutta et al., 2013), this chapter highlights the ethnographic approaches that I used to engage the study’s research questions. It also offers details regarding my choices to document and analyze the stories of African American hospice patients and their caregivers.

Chapters 3 through 6 describe the results of this study by focusing on specific aspects of study participants’ perceptions and experiences with hospice care. In the third chapter, “Hospice Disparities as an Extension of Structural Inequality,” participants describe hospice disparities as tied to inequality within the structure of the United States health care system. Chapter 4 is titled “Patients and Caregivers’ Decision-Making Narratives.” This chapter describes how patients and caregivers work within and around the formal health system to make initial decisions to use hospice services. The fifth chapter, “The Complexity of Hope: Patients and Caregivers’ Experiences with Terminal Illness and End-of-Life Care,” explores how participants’ make sense of their hospice

experiences through storytelling. Finally, Chapter 6 is titled “Building Partnerships to Address Disparities in Hospice Utilization” and focuses on the co-constructed solutions for promoting hospice utilization that emerged from my dialogic engagement with patients and caregivers.

In the final chapter, “Conclusions and Implications,” I return to the research questions that guided this study and provide an overview of how the present findings contribute to current understandings of hospice disparities. I also address the implications of this research for promoting hospice utilization and highlight directions for future research.

Chapter 1: Literature Review

In this opening chapter, I position this study within the existing literature on the underutilization of hospice by African Americans and describe how this project addresses important limitations of this research. I also offer an overview of the study's theoretical underpinnings by discussing the central tenets of the CCA and narrative theory. I begin, in the following section, by summarizing the history of hospice in the United States.

What is Hospice Care?

Palliative care is a medical specialty that focuses on providing treatment that enhances patients' comfort or quality of life and entails any therapy that focuses on providing relief from the symptoms, pain, and stresses of serious illness (Connor, 2009; World Health Organization (WHO, 2013). This approach uses a team-based, multi-disciplinary approach that involves input from physicians, nurses, social workers, psychologists, and other allied health providers. Palliative care can include a wide variety of treatments, including medication, spiritual counseling, and psychological therapy. Although palliative services are appropriate for any individual with a serious illness (regardless of the prognosis), perhaps the most recognizable form of palliative care in the United States is hospice (Connor, 2009).

Hospice is a specific form of palliative medical practice that offers a program of care for terminally ill individuals as they near the end of life (Connor, 2009). According to the National Hospice and Palliative Care Organization (2013):

[H]ospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well...Hospice focuses on caring, not curing and, in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations. (pp. 1-2)

Hospice is an appropriate program of care for individuals suffering from any terminal condition that is likely to end their life. In order to qualify for hospice services, two physicians must "certify" that an individual has less than six months to live if his or her illness runs its natural course. The patient's primary or treating physician and the hospice medical director most often provide this certification (Connor, 2009; NHPCO, 2012). In nearly all circumstances, the patient and his or her caregivers must also agree to forgo curative treatment and focus exclusively on palliative services (Connor, 2009). The determination of what constitutes "curative" treatment is evaluated on an individual basis, as patients can often receive treatments that are considered curative (e.g., antibiotics, radiation therapy) if the treatments are likely to improve quality of life (Connor, 2009).

Upon entering hospice care, a family member¹ or close friend typically serves as the terminally ill patient's primary caregiver (NHPCO, 2013a). Hospice staff members support these caregiving efforts by providing medical services and equipment (see Table 1.1 for an overview of reimbursed hospice services). Hospice organizations use a team-based, multidisciplinary approach to help family caregivers meet patients' physical, emotional, and spiritual needs (Connor, Egan, Kwilosz, Larson, & Reese, 2002; Marrone, 1997). Hospice teams typically include hospice physicians, nurses, home health aides, social workers, mental health professionals, chaplains, and (if needed) speech, physical, and occupational therapists (NHPCO, 2013a). Under the direction of the team physician, hospice team members provide services in their area of expertise. Nurses typically provide the majority of patients' medical care, including administering medication and assessing patients' physical condition. Licensed Clinical Social Workers and other mental health professional provide counseling to maintain patients/caregivers' psychological and emotional health. Home Health Aides and Certified Nursing Assistants support Activities of Daily Living (e.g., bathing, cleaning, grooming). Chaplains help patients and families with spiritual needs through religious study and counseling services. Volunteers are also an integral part of hospice teams (Foster, 2005; 2006). The Medicare Hospice Benefit requires that 5% of hospice workforces are volunteers. Volunteers serve a variety of functions within hospice organizations, including administrative services, social support, and respite care for caregivers (Connor, 2009).

¹ Hospice embraces a broad definition of the term "family member," which includes those connected emotionally, legally, and/or by blood relation (see Connor, 2009).

Table 1.1

Reimbursed Hospice Services (adapted from NHPCO, 2013a)

Pain and symptom management
Assistance for patients in dealing with the emotional, psychosocial, and spiritual aspects of dying
Counseling (including dietary, pastoral, and other)
Provide needed drugs, medical supplies, and equipment (e.g., hospital beds, shower chairs, wheelchairs)
Caregiving training for family members on how to care for the patient
Speech, physical, and occupational therapy when needed
Short-term inpatient care when pain or symptoms become too difficult to manage at home or the caregiver needs respite time
Bereavement care and counseling for surviving family and friends (up to 13 months following the patient's death)

A Brief History of Hospice

The roots of contemporary hospice care can be traced to 11th century Europe. The Knights Hospitallers established the first hospices to provide care for the sick and dying, and offer travelers from the Holy Land a place to rest (Connor, 2009). After falling away near the end of the Middle Ages, St. Vincent de Paul resurrected hospice care during the 17th century when he founded the Sisters of Charity in Paris. The hospice movement expanded during the 18th century, as the Irish Sisters of Charity founded Our Lady's Hospice in Dublin during 1897 and St. Joseph's Hospice in London eight years later (Foster, 2006). Dame Cicely Saunders, often credited as matriarch of the modern hospice movement, arrived to work at St. Joseph's Hospice in 1955. Based on her background in medicine and social work, she soon developed the philosophy that hospice should use a team-based approach to offer holistic end-of-life services to dying patients and their loved ones, a philosophy that would later become the backbone of the modern hospice

care (Connor, 2009). In particular, it was during this period that Saunders developed the concept of *total pain*, which recognizes that multiple sources and interventions are needed to address the physical, psychological, social, emotional, and spiritual pain associated with terminal illness (Gunaratnam, & Oliviere, 2009).

Hospice care first appeared in North America during the 1970s, amid growing dissatisfaction with the increasing medicalization of dying after World War II (Connor, 2009; Foster, 2006). During this period, significant advances in science of medicine, pharmaceutical and technological agents were used to prolong life at all costs and, ostensibly, attempt to eliminate death (Connor, 2009). In this climate, medical professionals increasingly lacked the skills to care for the dying and frequently treated death (and dying persons) as socially undesirable (Connor, 2009; Foster, 2006). Against this backdrop, the hospice movement emerged as a grassroots effort to “rehumanize the dying process” by offering a caring, holistic approach to end-of-life care (Foster, 2006, p. 16; see also Egan & Labyak, 2006).

After studying under Dame Saunders, Florence Wald (the former dean of the undergraduate nursing school at Yale University) opened Connecticut Hospice Inc., the first hospice in the United States, in 1971(Connor, 2009). A home care service soon followed in 1973. By the middle of the 1970’s, the hospice movement began to spread rapidly to various locations across the United States and Canada. Even in this early period, hospices in the United States demonstrated a “slant distinctly toward home care,” which reflected the general American preference to die at home (Connor, 2009, p. 5). The National Hospice and Palliative Care Organization (original known as the National Hospice Organization) was founded in 1978. The NHPCO soon established professional

guidelines for the establishment and conduct of hospice programs and began working to educate the public about the benefits of hospice care (Miller, Mor, Gage, & Coppola, 2000). In 1993, the NHPCO published *Standards of a Hospice Program of Care*. This document provided a comprehensive set of guidelines for achieving excellence in the provision of hospice care. Two years later, in 1995, the Joint Commission for Accreditation of Health Care Organizations began offering accreditation to hospice programs through its home health accreditation program (Connor, 2009). These events represented an important step forward in legitimizing hospice as a viable option for care at the end of life.

Perhaps the most significant factor in the development of the U.S. hospice movement was the creation of the Medicare Hospice Benefit in 1982 (Connor, 2009; Ragan, Wittenberg-Lyles, Goldsmith, & Sanchez-Reilly, 2008). Hospice care had previously only been available through out-of-pocket payment or charitable care. The addition of hospice as a Medicare benefit was initially controversial, as some feared that hospice would shift away its charitable roots and risk moving toward the type of medicalized model that the movement was attempting to resist (Connor, 2009). Although this has occurred to some degree, the addition of the Medicare benefit has also dramatically increased hospice access to a larger portion of the general population and is credited with increasing the legitimacy of this form of care (Connor, 2009; Moore, 1998).

Over the past 30 years, the hospice movement has been successful in becoming an integrated part of the U.S. health system and developing into a cost-effective, high quality end-of-life care option for dying patients and their loved ones (Chen, Haley, Robinson, & Schonwetter, 2003; Navari, Stocking, & Siegler, 2000). The number of U.S. hospice

organizations has grown to nearly 5,000 (Connor, 2009) and approximately 44.6% of all U.S. deaths occurred under hospice care in 2011 (NHPCO, 2012). Just over half (56%) of the patients were female and nearly 83% were 65 years of age or older (NHPCO, 2012). Patients with a primary diagnosis of cancer make up the largest portion (37.7%) of the hospice population; the top three specified non-cancer diagnoses were heart disease (14.3%), dementia (13%), and lung disease (8.3%), according to the NHPCO (2012).

As hospice utilization has expanded in the United States, a growing body of evidence suggests that individuals who receive hospice services are overwhelmingly satisfied with the quality of their end-of-life care. Over 75% of bereaved family members in 2010 rated hospice care as “excellent” on the Family Evaluation of Hospice Care (NHPCO, 2012), a survey measure developed by the NHPCO and Brown University’s Center for Gerontology and Healthcare Research (Connor, Teno, Spence, & Smith, 2005; NHPCO, 2012). Additionally, the composite score of global hospice quality across 17 core measures was approximately 87% (NHPCO, 2012). Measuring the quality of hospice care from the perspective of patients remains a challenge, but at least one study indicates that patients find hospice care effective in meeting their end-of-life pain needs. Using a distress scale of 0-10, a 1995 National Hospice Organization (now NHPCO) study found that patients’ average pain scores from 11 different hospice organizations was just 1.67 (range .51 to 4.1) in the last 30 days of life (Connor, 2009). In addition to providing high quality care, studies indicate that hospice can also address the need for cost-effective end-of-life care. One recent study indicates that hospice saves the Medicare program an average of \$2,300 per decedent, with a maximum savings of around \$7,000

for patients who received hospice care for seven weeks (Taylor, Ostermann, Van Houtven, Tulsky, & Steinhauser, 2007).

African Americans & Hospice: Disparities in Hospice Utilization

Despite the popularity and high quality of hospice care, many scholars have noted a significant disparity in hospice utilization by African Americans and other ethnic/racial minorities (see Table 1.2). Only 8.5% of the approximately 1.6 million patients who received hospice services in 2011 identified as African American (NHPCO, 2012). Although these numbers represent an increase in the use of hospice services by African Americans (up from 7.2% in 2008), a disparity in hospice enrollment remains, even as research has demonstrated that more than 92% of African Americans who use hospice services are satisfied with their care (Rhodes, Teno, & Connor, 2007). Furthermore, given that African Americans suffer from inequitable rates of three of the most common hospice diagnoses (i.e., cancer, heart disease, and stroke), one might expect them to be overrepresented among the hospice population (CDC, 2011; NCI, 2008; NHPCO, 2012).

Table 1.2

Percentage of Hospice Patients by Race (NHPCO, 2012)

Patient Race	2011	2010
White/Caucasian	82.8%	77.3%
Multiracial or Other Race	6.1%	11.0%
Black/African American	8.5%	8.9%
Asian, Hawaiian, Other Pacific Islander	2.4%	2.5%
American Indian or Alaskan Native	0.2%	0.3%

Disparities in hospice utilization are disconcerting because large numbers of African American patients die in hospitals and experience long periods of often futile, life-sustaining treatment, insufficient pain management, poor communication with health care providers, and increased health care expenditures (Flory, Yinong, Gurol, Levinsky, Ash, & Emanuel, 2004; Hogan, Lunney, Gabel, & Lynn, 2001; Taylor et al., 2007). These experiences are inconsistent with many African Americans' preferences to die at home while avoiding life-prolonging treatments with uncomfortable side effects (Barnato et al., 2009) and counter to the mission of hospice care, which is to improve the quality of life for all patients as they near the end of life (Connor, 2009; NHPCO, 2012).

Given the documented end-of-life preferences of African American patients and the high quality of hospice care, scholarly interest in the underutilization of hospice by African American patients and their families has increased over the past decade (Bullock, 2011; Yanchu et al., 2010). This research has confirmed that disparities in hospice utilization exist, even when controlling for patients' sex, education, marital status, existence of a living will, income, and health insurance status (Greiner, Perera, & Ahluwalia, 2003; Johnson, Kuchibhatala, & Tulsky, 2009). Studies that are more recent have explored African American patients' and their loved ones' decisions regarding hospice care (Bullock, 2011; Campbell, Williams, & Orr, 2010). Although this body of research is still relatively limited, the primary focus of these studies has been to provide a foundation for persuasive message campaigns and educational materials designed to promote informed decisions about hospice (e.g., Enguidanos et al., 2011; Johnson et al., 2009; Yancu et al., 2010). In particular, these studies have sought to identify cultural

factors that influence African Americans' perceptions/understandings of hospice care and hence serve as barriers to hospice utilization.

The most commonly cited barrier in these previous studies is limited knowledge of hospice services and the absence of communication about hospice care between African American patients and their family members and health care providers (Chung Essex, & Samson, 2009; Rhodes et al., 2006; Yanchu et al., 2010). In particular, these studies suggest that many African Americans may be unaware of services that are available through hospice (Born et al., 2004; Chung et al., 2009; Jenkins, Lapelle, Zapka, & Kurent, 2005; Smith, 2004; Taxis, 2006) and locations where the services are provided (Born et al., 2004; Bullock, McGraw, Blank, & Bradley, 2005; Jackson, Schim, Seeley, Grunow, & Baker, 2000; Taxis, 2006). Studies also indicate that many African Americans are unaware of how hospice care is paid for (Born et al., 2004; Bullock et al., 2005; Scharlach, Kellam, Ong, Baskin, Goldstein, & Fox, 2006) and the role of loved ones in caring for hospice patients (Bullock et al., 2005; Campbell et al., 2010; Smith, 2004; Taxis, 2006). Other studies have noted African Americans are less likely to have advance health care directives that offer explicit directions regarding their end-of-life care preferences (Greiner et al., 2003; Jenkins et al., 2005; Johnson et al., 2009). Additionally, previous research suggests that Christian spiritual beliefs common among African Americans may limit hospice utilization because it requires that both patients and their loved one acknowledge impending death (Winston et al., 2005; Yanchu et al., 2010). Other scholars have pointed to a systematic distrust of the U.S. health care system, based on a history of social injustice, as a factor that may limit hospice use (Blake & Darling, 2000; Gamble, 1997).

Existing research also suggests that a focus on quality rather than quantity of life differs from common African American preferences for longevity and the belief that suffering can be beneficial (Kagawa-Singer & Blackhall, 2001; Taxis, 2006; Teno et al., 2007; Winston et al., 2005). Although studies show that patient preferences for life-sustaining treatment over palliative care may be a common barrier (regardless of racial identity) to hospice admission, the ethic of struggle over surrender may be more important than quality of life among African Americans (Kagawa-Singer & Blackhall, 2001; Taxis, 2006; Teno et al., 2007; Winston et al., 2005). Thus, participants in previous studies have equated hospice enrollment with “giving up” on themselves or their loved ones (Taxis, 2007).

As noted above, the focus of these existing studies has been to identify barriers to hospice enrollment in order to develop health campaigns and educational materials that address these factors and promote African American hospice use (Born et al., 2004; Bullock, 2011; Enguidanos et al., 2011; Johnson et al., 2009; Rhodes et al., 2006; Yancu et al., 2010). Enguidanos and colleagues (2011) were among the first to move beyond the identification of barriers to hospice use. They created and pilot tested an educational brochure that targeted older, African Americans. The brochure included general information about hospice care and brief stories of African Americans’ hospice experiences. Using a pretest/posttest quasi-experimental design, the results of a pilot study indicated a positive increase in attitudes, knowledge, and intentions toward hospice care following exposure to the brochure among a small group of older African American adults (see Enguidanos et al., 2011 for detailed results).

Despite an increased focus on hospice disparities, African Americans' hospice utilization has remained static over the past five years (NHPCO, 2012). Given current inequities in the cost and quality of end-of-life care among African Americans and the potential for increased hospice use to address this issue, it is imperative that efforts to understand this disparity and to identify viable methods of promoting informed decisions about the hospice option continue (Bullock, 2011; Dillon et al., 2012; Enguidanos et al., 2011). Furthermore, although the current literature offers important insights into factors that may limit hospice utilization and points to potentially viable methods of increasing awareness of hospice services, it is limited by prevailing conceptualizations of culture, current understandings of health decision making, and an exclusive focus on promoting informed decisions through the dissemination of expert-created health promotion messages. I discuss each of these limitations in the following section.

Limitations of the Current Literature

Notions of culture had, for a long time, been absent in health communication research, as scholars and practitioners operated under universalist notions of health and communication (Airhihenbuwa, 1995; Dutta, 2008; Dutta-Bergman, 2004a, 2004b; Dutta & Basu, 2011; Lupton, 1994). As culture has emerged as a primary topic during the last decade, it has increasingly been incorporated “into how health communication is conceptualized, theorized, and practiced” (Dutta & Basu, 2011, p. 320). Similar to much mainstream health communication scholarship, research in the realm of African Americans and hospice care has generally adopted a view that positions culture as a static collection of values, beliefs, and practices that can be assigned to a defined group or geographic space (Dutta, 2007, 2008; Dutta & Basu, 2011). Consistent with what Dutta describes as the *cultural sensitivity* approach (see Dutta, 2007, 2008; Dutta & Basu,

2011), the focus of these studies has been to extract and isolate cultural barriers to hospice use in order to create educational campaigns designed to change individual attitudes, beliefs, and behaviors of terminally ill African American patients and their loved ones. For example, several studies highlight a cultural association between African Americans and Christian spirituality, which may lead patients and caregivers to pursue curative treatment while waiting on “God’s timing” rather than acknowledge the likelihood of impending death (Kagawa-Singer & Blackhall, 2001; Winston et al., 2005; Yanchu et al., 2010). In addressing the potential for spiritual beliefs to limit hospice use, scholars have highlighted the need to emphasize the religious history of hospice and spiritual services that are available through hospice care in campaign messages (Dillon et al., 2012; Winston et al., 2005; Yanchu et al., 2010).

The cultural sensitivity approach locates health issues at the individual level, and thus, offers solutions that promote individual-level behavior change rather than looking at the structural contexts of health experiences (Dutta & Basu, 2011). By focusing on modifying individual behaviors, the culture sensitivity approach ignores problematic social systems and structures that contribute to health disparities, such as access to medical care, access to health enhancing resources, structurally situated cancer risks (e.g., access to regular cancer screenings, Dutta, 2007; Dutta & Basu, 2011). Furthermore, this approach fails to account for the dynamic, communicative nature of culture, as cultural meanings are continuously (re)constructed through interaction across changing contexts and circumstances (Dutta, 2007, 2008; Dutta & Basu, 2011).

The hospice decision-making literature, particularly among African Americans, also suffers from an emphasis on isolating discreet factors that influence hospice

decisions instead of examining decision making as a communicative process (Ellis, 2000; Foster, 2006). Individuals do not experience life-threatening illness in isolation; they navigate these experiences within familial and relational systems that work in tandem to make sense of and cope with disruptions to familiar relational patterns through an ongoing process of making and sharing meanings (Miller-Day, 2011). Communication among terminally ill individuals and their loved ones plays a significant role in experiences at the end of life, as it impacts families' functioning (Martire, Lustig, Schulz, Miller, & Helgeson, 2004), relational satisfaction (Adams, 2007), and patients' outcomes (Liu & Gallagher, 2009).

By presenting hospice decision making as a consideration of end-of-life care options, the current literature does not adequately capture the “momentous, conflictful, ambivalent, frustrating and emotional” nature of illness and death, as they are experienced within personal relationships (Ellis & Bochner, 1999, p. 231). Like much health communication research in end-of-life contexts, the existing literature does not account for the ways individuals make sense of and assign meaning to physical decline (among caregivers and patients), emotions, and relational dynamics across the continuum of care through interaction with others (Ellis, 2000; Ellis & Bochner, 1999; Ragan et al., 2008). Thus, there is a need for additional research which considers communication about hospice among African American patients and their loved ones more “holistically, processually, and personally” (Ellis, 2000, p. 304; see also Miller-Day, 2011).

Current understandings of how to address hospice disparities are also limited in the existing literature. As noted above, the overwhelming recommendation for addressing this issue is the creation and dissemination of health messages/educational materials

designed for the African American population (Born et al., 2004; Bullock, 2011; Enguidanos et al., 2011; Johnson et al., 2009; Rhodes et al., 2006; Yancu et al., 2010). Although health messages and educational materials may offer valuable information about hospice care to African American patients and caregivers, the logic underlying these recommendations perpetuates the top-down, expert-driven approach that has dominated the health communication field (Dutta, 2007, 2008). According to Dutta (2007), this approach typically involves developing an agenda for the health communication program (such as creating an educational brochure), which addresses cultural variables of interest, and then evaluating the impact of the intervention based on criteria defined by the experts. Such an approach largely (or entirely) ignores the voices of cultural communities, which are treated as the “targets” of health communication interventions, and discounts the ability of these community members to identify viable, locally meaningful solutions to salient health issues (Dutta, 2008, 2012; Dutta & Basu, 2011; Dutta-Bergman, 2004a, 2004b).

As Basu and Dutta (2009) note, even health communication programs described as “participatory” often limit the involvement of community members to engaging in actions deemed appropriate by scholars and campaign planners. For example, some entertainment-education health campaigns² have been lauded for integrating the participation of community members in creating and testing messages (Jacobson & Storey, 2004; Storey & Jacobson, 2003); however, this form of “participation” fails to

² According to Papa and Singhal (2009), entertainment-education campaigns involve the “designing and implementing a media message to both entertain and educate, in order to increase audience members’ knowledge about an educational [or health] issue, create favorable attitudes, shift social norms, and change overt behaviors” (p. 187; see also Singhal & Rogers, 1999, 2002).

integrate the thoughts and ideas of cultural members in ways that do not fit experts' predetermined agenda (Basu & Dutta, 2009; Dutta, 2008). A similar approach is found in how Enguidanos and colleagues (2011) developed an informational brochure designed to promote hospice care among older African Americans. In this study, the authors determined that a brochure was an appropriate way to address knowledge, attitudes, and beliefs pertaining to hospice care. They asked community members to share personal stories about the hospice care, which the research team then edited to an appropriate length for the brochure. They continued by asking the same participants to offer feedback on the brochure's design/content and modified it accordingly (Enguidanos et al., 2011). Not questioned in this initiative is the notion that hospice disparities are not merely a function of deficient knowledge, attitudes, and beliefs that can be altered through disseminating information through the brochure. As Dutta (2008) argues, the evident goal "is persuasion on the basis of the problem and solution configurations as conceptualized by the senders of the message" (p. 54; see also Dutta-Bergman, 2004a, 2004b).

In light of limitations to the current literature and the pressing need to address disparities in end-of-life care, my dissertation project contributes to existing research on hospice decisions and experiences among African American patients and their loved ones. Moving beyond expert-driven understandings of and approaches to addressing hospice disparities, this study focuses on documenting the experiences of African American hospice patients and caregivers as they make sense of their experiences amidst the cultural and structural realities of their lives. This study also takes an initial step toward developing locally meaningful solutions to promoting informed decisions about hospice care by opening a dialogic space in which individuals can offer their thoughts

and opinions regarding how these efforts can best be carried out (Basu, 2010; Dutta, 2012). To accomplish these goals, I draw upon the culture-centered approach to health communication and narrative theory as theoretical foundations for this work, as these frameworks account for the dynamic, communicative nature of end-of-life experiences and foreground localized solutions to addressing health disparities (see Basu, 2010; Dillon & Basu, in press; Dutta, 2012).

The Culture-Centered Approach to Health Communication

Traditional health communication approaches adopt a linear, top-down model to study health disparities and develop health programs and policies (Airhihenbuwa, 1995; Basu, 2010; Dillon & Basu, In press; Dutta, 2008; Dutta-Bergman, 2004a; 2004b; Jamil & Dutta, 2012). As Jamil and Dutta (2012) note, these traditional models “prescribe one-way knowledge, information, and transmission of beliefs from the core health sectors” and academic centers to members of marginalized populations without considering the voices of marginalized individuals in meaningful ways (p. 369). Absent from such approaches are the voices of marginalized populations who are most affected by health inequities (Basu & Dutta, 2009; Dutta, 2007, 2008; Dutta & Basu, 2011). Grounded in the postcolonial and subaltern studies projects, the culture-centered approach privileges *localocentric articulations* (Basu, 2010; Dillon & Basu, in press) by engaging in a dialogic process of co-constructing meanings of health and working in solidarity with cultural communities to create avenues for social change (Dutta, 2012; Dutta & Basu, 2011).

Drawing on Airhihenbuwa (1995) and Lupton’s (1994) critiques of the dominant paradigm of health communication, the Culture-Centered Approach (CCA) argues that

research and praxis should focus on the dynamic interactions among culture, structure, and agency “as entry points to theoretical insights into how health decisions and meanings are negotiated in cultural communities” (Jamil & Dutta, 2011, p. 370). The CCA argues that these local articulations of health offer frameworks for developing culturally appropriate health policies and programs that seek to eliminate health inequities and improve access to health-promoting resources (Dillon & Basu, in press; Dutta, 2008).

In contrast to static understandings of culture in cultural sensitivity approaches, the CCA defines *culture* as a contextually situated, dynamic web of meanings that is continually (re)constituted through everyday interaction (Dutta, 2008; Geertz, 1973). These webs of meaning shape cultural members experiences of health and illness, as well health-related beliefs, values, and practices. Basu and Dutta (2007), for example, note how residents of Jharkhand (in rural eastern India) caught in a “twilight zone” between modernity and tradition frequently visit traditional healers, *ojhas*, for their health needs though many no longer accept traditional explanations for illnesses that these healers provide (e.g., insufficient animal sacrifice). Cultural meanings are also influenced by local social structures.

Structures are forms of social organizing that provide or limit individuals/communities’ access to resources that influence their health and well-being (Dutta, 2008). As Basu (2010) notes, examples of structures that influence health include available medical services, modes of transportation, communication channels, and health-enhancing resources (e.g., food, places to exercise, sanitary living conditions). Structures may also include avenues of civil society organizations and media platforms, as well as

national and international political actors and health policies (Basu & Dutta, 2008). These structural configurations, at all levels, often constrain the ability of marginalized to secure resources and engage in healthy practices (Basu, 2010; Dillon & Basu, 2013). For example, Basu (2010) describes how the structural conditions of poverty and inaccess to alternative means of securing income to provide for their children can lead commercial sex workers to engage in behaviors that may increase their risk of HIV, such as relenting to clients' requests for unprotected sex.

The goal of the CCA is to develop programs and policies that are consistent with marginalized communities' cultural frameworks in order meet their contextual needs (Dutta, 2008, 2012). Thus, culture-centered health communication research is founded on "a respect for the capability of the members of marginalized communities to define their health needs and to seek out solutions that fulfill these needs" (Dutta, 2008, p. 56). Within the framework of the CCA, as Dutta and Pal (2010) note, local meanings of health are articulated and understood through "dialogue" with cultural insiders. Central to this dialogic process is engaging with community members' everyday experiences by listening to the ways in which they narrate these experiences within their cultural and structural context (Basu, 2010; Dutta, 2008). Through narrating the ways cultural and structural frameworks enable/constrain opportunities for health, new possibilities emerge for social change in the healthcare context (Dutta, 2008). Given the centrality of stories and storytelling in understanding the interplay between culture, structure, and agency within individuals' lived experiences and opening possibilities for change, the CCA is intimately tied to narrative theory (Dutta, 2008).

Narrative Theory

Human life is storied life (Bochner, 2002; Coles, 1989). Humans “rely on stories circulating through our culture to make sense of our everyday lives and guide our actions” (Bochner, Ellis, & Tillman-Healy, 1997, p. 307). Buoyed by the crisis of representation across the social sciences and the move toward interpretive perspectives (Bochner, 1994, 2002), the narrative turn in the field of communication (as well as other social science disciplines) has accentuated the “significance of narrative as both a way of knowing about and a way of participating in the social world” (Bochner et al., 1997, p. 308). The crisis of representation (Clifford & 1988; Geertz. 1988; Turner & Bruner, 1986) provoked serious concerns about the validity and efficacy of the “correspondence theory of language” which underlies traditional approaches to scientific knowledge creation (Bochner, 1994; Bochner et al., 1997; Bochner & Waugh, 1995). This theory rests on the assumption that the language of science is capable of capturing a pre-existing world of external objects apart from the interpretation of the researchers who use it; that is, a belief the words used in scientific research “do not specify a world, but rather represent the world” (Bochner, 2002, p. 75). Kuhn (1962), however, argues that language is not a means to describe an external reality but “an ongoing and constitutive part of reality” (Bochner, 2002, p. 76; see also Bochner & Waugh, 1995). This recognition brought about an appreciation for how humans use language as tool for dealing with and making sense of their lived experiences (Bochner et al., 1997; Bochner & Waugh, 1995; Jorgenson & Bochner, 2004). Consistent with Geertz’s (1973) assertion that social science is “not an experimental science in search of law, but an interpretive one in search of meaning” (p. 5), Bochner (1994) argues that displaying how people do things in the

process of “making meanings” should be the central focus in the study of relational and health communication (see also Ellis, 2000).

A shift toward communication research that emphasizes meaning requires a focus on the ways individuals engage in the interactive and conversational work of (re)constructing meaning through narrative (Bochner, 2002; Bochner et al., 1997). As Arthur Frank (1997) writes, “Stories are the ongoing work of turning mere existence into a life that is social, and moral, and affirms the existence of the teller as a human being” (p. 43). Following Richardson (1990), Bochner (1994) suggests, “to have a self is to have a story and, usually, to want to tell your story to someone” (p. 30). In this process of narrating experiences and relationships, humans engage in acts of meaning (Bruner, 1990) in order to make sense of their existence (Freeman, 2010).

In addition to providing a framework for individual sensemaking, narratives also play a central role in shaping culture and cultural identity (Basu & Dutta, 2011; Dutta, 2008; Garro & Mattingly, 2000; Hoshmand, 2005). Narratives highlight the relationship between individual/relational experiences and cultural frameworks by attending to the “role of cultural forms in the creation of meaning” (Shore, 1996, p. 316). This suggests that the very fabric of stories and conversation (for example, the themes and guidance provided by the “point of the story”) is not just content but also the process through which cultural norms are created and propagated (Dutta, 2008; Garro & Mattingly, 2000). Stories offer insight about what it means to be a member of a culture, as it is through stories that cultural members pass on traditions, values, beliefs, and practices (Dutta, 2008). Garro and Mattingly (2000) note:

...hearing narrative accounts is also the principal means through which cultural understandings about illness – including possible causes, appropriate social responses, healing strategies, and characteristics of therapeutic alternatives – are acquired, confirmed, refined, or modified (p. 26).

Thus, cultural knowledge informs stories while stories link personal experience to cultural meaning (Dutta, 2008; Garro & Mattingly, 2000).

Narratives also provide a vehicle for experiencing and making sense of institutional structures that influence health and illness, as stories are deeply embedded in the various structures in which they occur (Dutta, 2008; Garro & Mattingly, 2000; Saris, 1995). In the case of illness, particularly terminal illness, treatment settings and health care institutions form an important part in the social world and stories that are told (Ellis, 2000; Garro & Mattingly, 2000). Despite the centrality of structures to cultural narratives, Dutta (2008) argues that this relationship is under-theorized in the current literature. He argues that one important contribution of the CCA is the recognition “that narratives are enacted within structural processes, and hence provide openings” to interrogate and transform oppressive social structures (Dutta, 2008, p. 114-115).

Human beings are not condemned to live out particular stories, even powerful canonical narratives, without hope for change (Bochner et al., 1997; Bruner, 1990). Part of the power of narrative is the ability to account for how one’s actions deviate from alternative narratives in ways that make them seem reasonable or justified (Bruner, 1990). As Bochner and colleagues (1997) note, social actors continually (re)create the social world through introducing new stories and altering existing narratives within particular cultural and structural systems. Through this dynamic, communicative process, narratives offer insight into the ways cultural members make sense of their health

experiences while offering opportunities for transforming oppressive structures (Basu, 2010; Dutta, 2008, 2012).

Research Questions

In highlighting the dynamic, communicative interplay between culture, structure, and agency, the CCA offers an appropriate framework for addressing the limitations to current literature regarding hospice utilization among African Americans. Furthermore, by respecting the capacity of patients and caregivers to define their health needs and seek out solutions that fulfill these needs, the CCA provides entry points for developing health programs and policies that are consistent with participants' cultural frameworks and meet their contextual needs. Informed by the CCA and narrative theory, the following research questions guide the present exploration of hospice disparities among African Americans:

RQ1: What are African American hospice patients' and caregivers' perceptions of disparities in hospice utilization?

RQ2: How do African American patients and caregivers describe their decisions to use hospice care?

RQ3: How do African American patients and caregivers describe their experiences with hospice care?

RQ4: What strategies do African American hospice patients and caregivers suggest for addressing disparities in hospice utilization?

Conclusion

Amidst the landscape of persistent inequities in end-of-life care, it is imperative that health communication scholars use their tools and platforms to address these alarming disparities. These efforts, however, must move beyond "identifying the best

strategies for providing vulnerable populations with relevant health information and support” (Kreps, 2012, p. 496), as some have suggested. Drawing on the research questions above, this study takes an initial (yet important) step toward understanding disparities in hospice utilization from the perspective of African American hospice patients and caregivers as well as working toward meaningful solutions to address this issue. In the next chapter, I provide an overview of the methods used to conduct this dissertation study.

Chapter 2: A Culture-Centered Methodology

The culture-centered approach (CCA) explores the dynamic relationships between culture, structure, and agency by engaging the narrated health experiences of marginalized communities (Dutta, 2008). Through this process, CCA researchers work in solidarity with community members to define relevant health issues and work toward local meaningful solutions that promote social change (Dutta, 2012; Dutta & Pal, 2010). This activist orientation is embedded in the dialogic methods CCA researchers use to produce knowledge through health communication scholarship. This chapter offers a detailed overview of the methodological choices I made to conduct this study. I begin by grounding my methodological approach within the framework of the CCA. I then proceed by discussing my research partnership with Quest Hospice, a large hospice provider in the southeastern United States. Finally, I describe the specific procedures I used to collect and analyze study data.

Methodological Approach

The methodological approach of this study is grounded in the tenets of the culture-centered approach. As noted in the first chapter, the CCA moves away from traditional, expert-driven health communication praxis that is often disconnected from the lived experience of marginalized by “listening to the voices...that have hitherto been unheard in policy and programming circles” (Dutta et al., p. 160; see also Dutta, 2008;

Dutta-Bergman, 2004a; 2004b). Aligned with the critical ethnographic stance of Conquergood (1989, 1991) and Madison (2005), I followed previous CCA studies in adopting a reflexive approach, which positions ethnography as a political tool for engaging with the health experiences of marginalized communities and challenging the structural configurations that promote health disparities (Basu, 2010; Basu & Dutta, 2009; Dutta, 2008; Dutta et al., 2013).

The entry point for addressing health disparities from a culture-centered perspective is a process of dialogic engagement between health communication researchers and local communities, a process which foregrounds community voices in understanding health issues and implementing locally meaningful solutions (Dutta, 2012; Dutta-Bergman, 2004a, 2004b). As Dutta et al. (2013) note, this process often begins by developing partnerships with community organizations to address relevant health issues, such as hunger (Dutta, 2012), HIV/AIDS (Basu, 2010; Basu & Dutta, 2008, 2009), or poverty (Jamil & Dutta, 2012). CCA researchers then deploy ethnographic research methods, such as in-depth interviews, participant-observation, and focus groups, to listen to and document the community members' health narratives, paying particular attention to the ways cultural/structural frameworks influence health meanings and practices (Basu, 2010; Basu & Dutta, 2008, 2009; Dutta, 2008; Dutta et al., 2013). Central to the dialogic process of CCA research is an acknowledgement of the researcher's positionality and the co-constructed nature of health meanings that emerge through these interactions.

Traditional ethnographers generally attempt to maintain a scientific stance of objectivity and distance, so as to avoid contaminating the research with their own presence or biases (Lindlof & Taylor, 2011; Van Maanen, 1988). In contrast to such

approaches, the reflexive ethnographic stance advocated by the CCA centers on a mutual, reciprocal relationship between researchers and community members as they co-construct meanings in the discursive space (Basu, 2010; Dutta, 2008). Co-construction, here, describes “a process of collaboration and power sharing between academics and marginalized communities” (Dutta et al., 2013, p. 160). In this spirit of collaboration, the CCA researcher does not isolate elements of human experience as discrete variables for the purpose of measurement and prediction from a detached position; instead, CCA scholars adopt a activist orientation in which they actively partner with disenfranchised communities to promote health equity (Dutta, 2008; 2012).

Tied to Jackson’s (1989) observation that “our understanding of others can only proceed from within our own experience” (p. 17), the dialogic partnerships advocated by the CCA require that researchers be acutely aware of relations of power throughout the research process (Basu, 2010; Basu & Dutta, 2008). For me, this meant "being acutely aware of power—who has it, how it is used, what it does, how it is revealed and obscured in discourse, and how I, as a researcher, reify and/or resist it" (Ellingson, 2005, p. 12; see also Dutta & Basu, 2013). Human beings are always historically and locally situated in cultural categories, including gender, race, and sexual identity, during any interaction. My social privilege as a white, heterosexual male who has experienced abundant access to material and educational resources is part of who I am and inevitability affects all aspects of my life, including research activities (Bochner, 1994, 2002). As Goffman (1959) notes, my presentation of self is made up of things I can and cannot change. I knew I could not cast my privilege aside or pretend that it does not matter. Nor could I

hide behind the illusion that unmediated objective truth is a possibility (Bochner, 1994, 2002).

I could commit, however, to continually questioning and interrogating the ways my subjectivity influenced the research process and enact a dialogic position of openness, honesty, and respect toward the hospice patients and caregivers who invited me to interact with them (Basu, 2010; Buber, 1998, 2002; Dutta, 2008; Dutta & Pal, 2010). I reflect on this notion in an excerpt from my research journal:

Today's interview with Jasmine was an interesting one. As she talked about not having health insurance for long periods of her life and experiences of discrimination in the health system, she nonchalantly mentioned that I "probably had no idea what that was like." It stung a bit to hear her say it, but I told her she was right. I said, "I don't know what that is like, but I am willing to listen." She told me she appreciated the chance to share her experiences. The exchange ended in a polite manner, but it was a good reminder of how my privilege limits my ability to identify with the individuals who share their time and stories with me. I found myself thinking of Buber and his call to "boldly swing into the lives of others." Even as I attempt to do this, however, it is important for me to remember that it is my privilege that allows me to swing right back out of these experiences. I know I will never understand discrimination in the same way as those who are taking part in this study, but, as I told Jasmine, I am willing to listen and keep trying.

As Dutta et al. (2013) note, culture-centered research centers on the acknowledgement that the voices of marginalized populations are often overlooked in

mainstream health discourses and this absence is intertwined with material disenfranchisement and health inequities. Through dialogue, CCA researchers co-construct health narratives with marginalized populations in order to introduce alternative articulations of health in the dominant knowledge frameworks and work to transform the structures that create and perpetuate marginality and health inequities (Dutta, 2008, 2012). Thus, in opposition to expert-driven knowledge production and intervention, this study represents a partnership with Quest Hospice as well as African American patients and caregivers who accessed Quest's services. Ultimately, this partnership is aimed at developing greater understanding of disparities in hospice utilization and taking an initial step toward address inequities in end-of-life care. In the following section, I discuss my partnership with Quest and describe how this organization facilitated my connection with the African American hospice patients and caregivers who took part in this study.

Research Site

Quest Hospice³ is a comprehensive hospice organization that services four counties surrounding the metropolitan area of a large city in the southeastern United States. Quest is part of a larger non-profit, post-acute care system that also provides palliative and senior independence services. Quest has a stated mission to offer high quality hospice care in order to address the needs of those affected by life-limiting illnesses and end-of-life issues. Since opening in 1983, Quest has grown to become one of the largest hospice organizations in the United States. Quest's patient population totaled nearly 7,000 in 2011. Of these patients, more than 73 percent self-identified as

³ The names of all health care organizations, providers, patients, patients' caregivers, and all other incidental characters are pseudonyms used to protect the privacy of my research participants.

Caucasian/White, 14 percent self-identified as Hispanic, and 9.8 percent self-identified as African American.

Like most U.S. hospice organizations, Quest primarily provides home-based care rather than inpatient services. Consistent with accepted end-of-life care practices and the hospice philosophy, Quest uses an interdisciplinary care approach that includes a medical director, nurses, social workers, a chaplain, home health aides, therapists, and bereavement counselors. These integrated care teams coordinate ongoing health services that encompass physical, spiritual, social and emotional needs, continually responding as the illness progresses. In addition to these employees, Quest also relies on hundreds of volunteers that provide a variety of services including home care, nursing home care, administrative services, fundraising, bereavement counseling, and community education.

Entrée

A crucial aspect of any community-based or field study is gaining access to a research site and population, a process ethnographers often refer to as “entrée” (Warren & Karner, 2010). The genesis of my partnership with Quest began in the spring of 2011. As part of my doctoral studies at the University of South Florida, I completed a seminar entitled “Communicating at the End of Life” with Dr. Lori Roscoe. Guided by Farmer’s (2003) notion that the ability to pursue health is a fundamental human right, my research interests were shifting toward a focus on documenting and understanding how communicative actions (re)construct societal injustice in relation to health disparities when I began the course. I met with Dr. Roscoe early in the semester to discuss how I might extend my interest in health disparities to the context of end-of-life. During our conversation, she suggested that I look into racial and ethnic disparities in hospice utilization. Based on her recommendation, I completed a synthesis of qualitative research

related to hospice use among African Americans as my semester-long project (see Dillon et al., 2012). As I completed this project, I noticed several limitations in the existing literature and felt that adopting a culture-centered, communicative approach to this issue would offer an important research contribution as well as produce viable methods of promoting increased equity in hospice use.

Near the end of the semester, I met with Dr. Roscoe again and told her that I was interested in conducting a primary study of African Americans' hospice use as my dissertation project. She encouraged me to apply for a graduate assistantship from the Center for Hospice, Palliative Care and End-of-Life Studies at the University of South Florida (henceforth End-of-Life Center). In order to apply for this funding, I would need an organization that was interested in collaborating with me to complete the study. Dr. Roscoe had previously collaborated with Quest Hospice on several research projects and suggested that we inquire about their interest in working with me. After reviewing additional research and formulating tentative objectives for this study, Dr. Lori Roscoe and I met with Quest's Chief Medical Officer and Research Director to discuss the project in the summer of 2011. I received official notification that Quest would collaborate with me shortly after our meeting. The End-of-Life Center awarded me their competitive research assistantship in fall 2011, which provided yearlong research funding for 2012. In addition to completing my study, the assistantship required that I serve as a Research Intern with Quest. Prior to beginning the internship, I spent the last few months of 2011 applying for and receiving study approval from the Institutional Review Board (IRB; see Appendix A for IRB approval letter).

I attended Quest's new employee orientation in January 2012. The orientation, which included various workshops, a physical health screening, criminal background check, and electronic medical record (EMR) training, lasted approximately two weeks. Attending orientation was a valuable opportunity. In addition to familiarizing me with organizational policies and procedures, the training helped prepare me for the experience of visiting patients' home and interacting with them and their families. Furthermore, being introduced to organizational members in a similar manner to a new employee seemed to diminish their sense of me as an "outsider," as I was treated like any other member of Quest's research department. In addition to completing this study, my position as a research intern included providing 80 hours of unpaid service hours. These hours were spent conducting literature reviews, writing/editing grant proposals, and quantitative data analysis. Having received IRB approval and completed the orientation requirements, I was ready to begin interacting with patients and families and listening to their hospice stories.

Procedures

Recruiting participants. Given that hospice organizations consider both patients and caregivers to be the unit of care and the active role that primary caregivers play in making decisions about and providing hospice care (Campbell et al., 2010; NHPCO, 2013a), I chose to include patients and primary caregivers in the study. Identifying patients and caregivers to participate in this study was a lengthy and complex process. When I began the study in late January, 2012, I worked with a research nurse to create a

list of all hospice patients and their primary caregivers from the previous six months⁴ using Quest's EMR system. After downloading this list to Microsoft Access, I then screened participants by eliminating all patients who did not self-identify as Black/African American. This initial screening produced a contact list of 412 patients and 389 primary caregivers. Approximately 40% ($n = 163$) of the patients were living at the time of this screening.

Using this patient/caregiver list, I continued screening patients and caregivers for participation using the EMR system. Consistent with Quest's research guidelines and my IRB protocol, I considered patients cognitively able to participate if they scored more than 80% on the Short Portable Mental Status Questionnaire⁵ (SPMSQ; Pfeiffer, 1975), information that was available in patients' medical record. In addition to screening patients' cognitive functioning, I adopted what the Quest research nurses called a "common sense" approach to identifying potential participants. This meant that I did not include patients who were rapidly deteriorating, had just experienced a significant transition (e.g., from their home to an inpatient facility), or had previously declined to participate in research studies. Once again, this information was available in the patients' medical records.

After this second round of participant screening, I contacted a Quest staff member to ascertain the appropriateness of each patient/caregiver. Before contacting patients, I spoke with each patient's primary nurse and asked if there was any reason he or she believed I should not invite the patient to participate. There was only one occasion where

⁴ This patient/caregiver list was stored in electronic format on Quest's secure network and protected by two passwords, which only the research nurses and I could access.

⁵ The Short Portable Mental Status Questionnaire is an established measure of cognitive functioning (see Pfeiffer, 1975).

a nurse suggested I not contact a patient (due to the patient's deteriorating mental health). For surviving caregivers, I checked with the director of Quest's bereavement program. Based on his suggestion and Quest's research standards, we agreed that I would not contact caregivers until two months had passed since the death of their loved one and a bereavement counselor had contacted them. Ultimately, there were four instances when the director suggested I not contact a caregiver because of his or her difficulty coping with the loss.

After getting permission from the nurse or bereavement director, the next step in the process was to contact patients and/or caregivers. I made initial contact with potential participants by telephone⁶. During the call, I explained the nature of the study, answered questions, and asked if he or she was interested in participating. If the patient/caregiver expressed interest in participating during the telephone conversation, I proceeded by engaging in a more in-depth research preview discussion (Yassour-Borochowitz, 2004). As Yassour-Borochowitz (2004) explains, "the purpose of this preview is to describe in detail the research goals and procedure and to discuss with the participant the applications of participating in such a project" (p. 182). These conversations also included highlighting the importance of informed consent for both participants and researchers. Instead of setting up a meeting during the preview conversations, I asked potential participants to call me back to set up the meeting once they had considered if they wanted to be part of the study.

⁶ I attempted contact each patient/caregiver a maximum of three times. If I did not reach the individual, I left a detailed message during the second attempt and then followed up one last time. If I did not reach the patient/caregiver after three attempts, I eliminated the individual from the participant list.

I stayed in close contact with each patient's primary nurse and the bereavement director as I scheduled these meetings. I made sure they were aware anytime I was going to visit a patient/caregiver. In a small number of cases ($n = 4$), I was able to make my initial visit with the patient's nurse, which allowed him or her to introduce me to the patient and his or her caregivers. Although this process seemed helpful, it was often difficult to coordinate visits with the nurses, and I ended up visiting the majority of patients and caregivers on my own.

During these initial visits, I further explained the study and answered any questions that patients and/or caregivers had about participating. I also provided them with two copies of a written informed consent form so they could consider if they wanted to take part in the study. After explaining the study and informed consent procedures, I offered potential participants the chance to sign the form immediately or to take as much time as they wanted to consider participating. About half of the eventual participants ($n = 14$) chose to sign the form immediately while the remaining participants ($n = 16$) took up to a week to contact me for a second visit. All participants provided written informed consent prior to taking part in the study.

Participants. Thirty individuals chose to take part in this study. This sample of 30 participants included 14 hospice patients (see Table 2.1) and 16 primary caregivers (see Table 2.2), all of whom self-identified as Black/African American, according to Quest's medical records. Three additional patients agreed to participate but died before they were able to do so.

Table 2.1

Participants: Patients (N = 14)

Name	Primary Diagnosis	No. of Interviews
Charles	Heart Disease	4
Leroy	Heart Disease	3
Jane	Cancer	3
Kevin	Cancer	1
Lisa	Kidney Disease	1
Betty	Lung Disease	1
Jeannie	Lung Disease	1
Martin	HIV/AIDS	1
Katherine	Cancer	1
Mandy	Cancer	1
Carolyn	Lung Disease	0
Joan	Unspecified	0
Stephen	Cancer	0
Rose	Heart Disease	0

Table 2.2

Participants: Caregivers (N = 16)

Name	Relationship to Pt. (Name)	No. of Interviews
Carla	Daughter (Patricia)	3
Richard	Son (Harriet)	3
Bridget	Daughter (Linda)	2
Robert	Nephew (Valerie)	2
Belle	Daughter (Curtis)	1
Jack	Spouse (Lisa)	1
Roger	Son (Elizabeth)	1
Geraldine	Daughter (Betty)	1
Keisha	Niece (Karen)	1
Milton	Nephew by marriage (Karen)	1
Jasmine	Sister (Martin)	1
Ruth	Spouse (David)	1
Pearl	Spouse (George)	1
Carl	Son-in-Law (Betsy)	1
Julia	Daughter (Betsy)	1
Jason	Friend (Olivia)	1

Five of the patients participating in the research were male and nine were female. Among the primary caregivers, nine were female and seven were male. The patients' mean age was 69.8 years, with a range of 29–81 years. Caregivers' ages ranged from 34–76 years, with a mean age of 46.3 years. The majority of participants (26) identified their religious affiliation as Protestant, two said they were Catholic, and two reported they were Jehovah's Witnesses.

Although I did not intentionally stratify the sample by patient diagnosis, primary diagnoses among the patient sample were consistent with the national average for cancer/non-cancer patients in hospice care. According to the NHPCO (2012), approximately 37.7% of hospice patients in the United States had a primary diagnosis of cancer. Within this study's sample, five patients (35.7) were admitted to Quest with cancer as their primary diagnosis.

As of December 2012, nine of the 14 patients who took part in the study were deceased. Of the remaining patients, Lisa was discharged because she could not be recertified to hospice care, Betty voluntarily withdrew from Quest's care, and Kevin moved to another hospice organization after relocating to Atlanta, Georgia to live with his daughter. Leroy and Katherine were still receiving services from Quest.

Data collection. Ethnography is a genre of qualitative research that does not imply any particular method (Lindlof & Taylor, 2011) but describes research with a goal of describing and interpreting the observable relationships between social practices and systems of meaning based on firsthand experience and exploration of a particular cultural setting (Atkinson, Coffey, Delamont, Lofland, & Lofland, 2001). Consistent with previous culture-centered studies, the primary ethnographic data collection method for

this study was in-depth interviewing. Field notes and reflexive journal entries supplemented the interviews (Basu, 2010; Basu & Dutta, 2009; Dutta, 2012).

I used field notes to document unrecorded conversations, recount interactions between patients and families (or hospice providers), and describe the physical surroundings in which interviews took place. I compiled field notes immediately following each interaction with patients and caregivers; in most cases, I would pull into the closest public parking lot and write in my notebook while sitting in front seat of my car. I ended up with just over 40 pages of handwritten notes (see Appendix B for a sample of my field notes). The journal entries included reflections on interviews, initial themes/writing ideas, thoughts on challenges in the field, and questions for future interviews. Ultimately, I used the journal as a means of promoting "an internal dialogue for examining critical issues that emerged" during the research process (Basu, 2011, p. 395; see also Conquergood, 1991; Koch, 1996; Koch & Harrington, 1998; Paterson, 1994). I did not keep a specific schedule and format for journal writing. I wrote some notes freehand and typed others on my laptop whenever I felt inspired to do so. The journal ultimately contained approximately 20 handwritten and 25 electronic pages (see page 47 for a sample journal entry).

Although the field notes and journal entries were essential to the research process, the core data was drawn from formal and informal interviews with study participants. Of the thirty individuals who took part in the study, ten patients and 16 caregivers took part in formal, in-depth interviews (Lindlof & Taylor, 2011). I used an interview technique Gunaratman (2009) describes as narrative interviewing, which combines the unstructured and semi-structured interview formats. Each interview began with a grand tour question

(McCracken, 1988; Spradley, 1979) meant to invite participants' to share their stories while imposing limited a priori categorizations on their narratives (Fontana & Frey, 2003). The grand tour question for this study was: Could you tell me the story of how you got the point where you felt that hospice was an option for [you or your loved one]? As participants shared their stories, I used spontaneous probes in order to gain greater insight into their experiences. Most of the interviews continued in this free-flowing form. When necessary, the interviews continued in a semi-structured format (Lindlof & Taylor, 2011), meaning that I introduced general topics and guided the discussion by asking specific questions (see Appendices C and D for copies of IRB-approved interview guides).

I conducted multiple interviews with seven participants. Among the patients, Leroy and Jane took part in three interviews each while Charles participated in four. Two primary caregivers, Carla and Richard, invited to me to interview them three times, and Bridget and Robert took part in two interviews. These conversations were even less formal than our initial interviews. I generally asked questions about our previous conversation, offered initial interpretations of the participants' stories, and gathered their opinion regarding thoughts and experiences other participants shared with me. In most cases, I found that the patients and caregivers had also thought of things they wanted to share with me after completing our first interview and were eager to do so.

The majority of participants' chose to be interviewed at home ($n = 24$). I conducted the other interviews in a private office at one of Quest's office buildings. Three participants, Carl, Julia, and Jason, felt uncomfortable with me recording their interviews but did provide permission for me to take detailed notes and use their stories in the analysis and written results. Including those who took part in multiple interviews,

patients and caregivers participated in 36 recorded interviews spanning over 24 hours. Interviews lasted between approximately 15 minutes and 3 hours, with a mean interview time of approximately 37 minutes. Four additional patients invited me to come visit them in their homes but did not feel well enough to participate in a formal interview. Like those who declined to be recorded, however, they did answer a few questions and offered permission for me to share stories or insights from our informal conversations.

Analysis and writing procedures. I analyzed the interview transcripts, field notes, and journal entries jointly through a process informed by constructivist grounded theory (Charmaz, 2000, 2006), a framework well suited to the culture-centered focus of this project (Basu, 2011; Dutta, 2012). As Charmaz (2006) describes, “grounded theory methods consist of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories grounded in the data themselves” (p. 2). Grounded theory first emerged from the work of Glaser and Strauss (1967) as a qualitative method imbued with positivist assumptions that emphasized objectivity, generalizability, and discovering an external, knowable world (Charmaz, 2006). Aligned with “postmodern, constructivist, feminist, [and] critical race theory critiques of the politics of the production of knowledge” (Ellingson, 2005, p. 159), Charmaz’s (2006) constructivist grounded theory is a method that:

places priority on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants...[it] also acknowledges that the resulting is an interpretation...The theory *depends* on the researcher’s view; it does not and cannot stand outside of it. (p. 130)

This revised method fit with the culture-centered, reflexive ethnographic approach of this study by allowing me to make sense of participants' narratives while acknowledging that my positionality inevitably influenced the meanings that emerged from the research process.

Data analysis began concurrently with conducting interviews, taking field notes, and journaling. I followed the steps of grounded theory analysis, as outlined by Charmaz (2006) and Ellingson (2005): coding data, developing inductive categories, revising the categories, writing memos to explore preliminary ideas, comparing data to existing literature, fitting data into new and existing categories, identifying where data did not fit, and revising the categories. Throughout the process, I discussed emerging themes and ideas with participants during subsequent interviews and informal interactions, a process akin to "member checking" (Lincoln & Guba, 1985). This procedure aligned with the co-constructed focus of CCA research while offering a level of analytical transparency that is atypical in traditional social science research (Dutta, 2008).

Through an intensive reading of the individual codings, I used the constant-comparative method to refine categories by clumping and reorganizing them until a tree of large-order and small-order themes began to emerge from the data (Charmaz, 2006). Through this process, I paid particular attention to how initial categories "differentiated from each other, how they interrelate[d], and how full (or empty) of compelling evidence" the categories were (Lindlof & Taylor, 2011, p. 251). I continued revising the analytic themes until I reached a point of theoretical integration, a moment Morse (1994) describes as the emergence of the "best" theoretical scheme. From Morse's (1994) perspective, the "best" theoretical scheme is one that "provides the best comprehensive,

coherent, and simplest model for linking diverse and unrelated facts in a useful, pragmatic way” (p. 32).

In producing the written account of this ethnographic study, I followed Dutta’s (2008) contention that the primary objective of CCA research is to create communicative spaces where “those voices that have traditionally been silenced by mainstream health communication projects” (p. 265) would be foregrounded. In introducing these voices into the mainstream health system, culture-centered projects engage organizational leaders and policymakers with perspectives that question taken-for-granted assumptions and offer strategies to address structural inequities. Thus, even as the CCA questions and interrogates power differences in academic/health sectors, culture-centered research is pragmatic in the sense that it makes use of the privileged status of scholars, like me, to access platforms that can foster awareness of participants’ articulated health needs and inspire actions aimed at promoting social change (Dutta, 2008). Consistent with these aims, I privileged the narratives that emerged from my dialogues with patients and caregivers in this manuscript (albeit through the discourse of academic convention). I did not seek to offer a “view from nowhere” or present an uncontaminated external reality (Ellingson, 2005; Haraway, 1988); I did, however, decide that offering a co-constructed analysis of participants’ narratives was the most valuable contribution I could make at this point. Resting on the culture-centered nature of this project and my activist orientation, I chose to focus this manuscript on the perspectives and experiences of the hospice patients and caregivers who offered to share a portion of their life with me.

I also identified with Dutta-Bergmann’s (2004b) struggle to write in ways that honored the nuances of participants’ individual experiences while feeling the need to

aggregate these experiences under the general labels like “African American,” “hospice patients,” and “caregivers.” Interestingly, Carla (caregiver) disclosed a similar tension after we completed our second interview. I describe this conversation in my journal:

I am not sure if she knew I meant it, but I was sincere when I told how much I appreciated her honesty in telling me her struggle with this study. I have made it a practice to ask participants if there is anything else they want to share before I leave. I had everything packed up and a hand on the doorknob before she chimed in with her response. She said something similar to, “You wanna know what’s hard about answering your questions?” I told her I did. “It’s like I’m kind of torn between just talking about myself and wanting to speak all of us, the Black community. I know we don’t always like getting lumped together but sometimes it does some good.”

Keeping Carla’s perspective in mind, I followed Dutta’s suggestion, (based on Spivak’s (1988) notion of *strategic essentialism*), to not lose sight of the importance of individual experiences while also accepting that a certain level of aggregation in culture-centered research is strategically “essential in order to impact any policy-level decision making, which is a critical goal of this work” (Dutta-Bergman, 2004b, p. 247). Thus, the findings presented in this manuscript proceed from an acknowledgement of the necessity yet impossibility of capturing the nuances of individual experience in an aggregate analysis. Like Carla, however, my ultimate hope is that this written account “does some good” in addressing hospice disparities.

Conclusion

In review, as the United States' population grows older and more diverse, there has been increasing concern regarding disparities in the cost and quality of end-of-life care among African Americans. Hospice care provides high quality, cost-effective care at the end of life, but African Americans underuse these services. In partnership with Quest Hospice, this study seeks to understand and takes steps toward addressing hospice disparities. Grounded in the CCA, I explore co-constructed narratives that emerged through dialogue with African American hospice patients and caregivers, my reflexive journal entries, and field notes to engage with the four research questions that guide this study. In the following chapter, I discuss how study participants situate disparities in hospice utilization as an extension of social inequality within the structure of the U.S. health system.

Chapter 3: Hospice Disparities as an Extension of Structural Inequality

Awareness of racial/ethnic disparities in health outcomes and service utilization is relatively limited among the general United States' population (Benz, Espinosa, Welsh, & Fontes, 2011). The patients and caregivers who took part in this study, however, were aware of the limited use of hospice by African American patients and their families. Based in their own experiences, the patients and caregivers I spoke with expressed agreement with existing studies that suggest a need to increase awareness and utilization of hospice services among African Americans (Born et al., 2004; Chung et al., 2009; Jenkins et al., 2005; Smith, 2004; Taxis, 2006; Yanchu et al., 2010). They did not, however, equate hospice disparities solely with individual knowledge deficiencies or cultural barriers, as these previous studies have done. Instead, the participants perceived that hospice disparities were tied to inequality within the structure of the formal U. S. health care system.

This section explores patient and caregiver narratives that explain perceptions of and access to hospice among African Americans. In doing so, it responds to the study's first research question, *RQ1: What are African American hospice patients and caregivers perceptions of disparities in hospice utilization?* This chapter begins with an examination of limited access to high quality health services. It then explores how this access influences hospice utilization. I then explain how participants equate the hospice

philosophy, itself, with inequality in the health system. Finally, I discuss how poor communication between providers and patients also contributes to hospice disparities.

Existing at the Margins of the U.S. Health System

In discussing disparities in hospice utilization, participants noted that these disparities are intertwined with structural inequities that push many African Americans to the margins of the U.S. health system. Several participants described themselves and/or close friends/family members as being excluded from the health system at times because they lacked the financial means to seek formal health care. As Katherine, a hospice patient with cancer, told me:

For the longest time, most of my life, in fact, I didn't really think about health as something to do with doctors or anything. I only remember being in a hospital one time when I was young; I wasn't even born in a hospital...I don't think it's quite the same for as many Black people anymore, but I still got family and friends who never been or don't got access to hospitals.

Leroy, a hospice patient with heart disease, shared a similar experience: "I was always just outside that cut off where you could get that medi-whatever coverage but not making enough to get insurance any other way." Leroy went on to explain that he had not seen a doctor in more than a decade before intense chest pains led him to seek medical care. At this point, Leroy discovered the heart condition that eventually led him to hospice care. Thus, for study participants, health meanings, including those associated with hospice, proceeded from an understanding that many African American do not have access to mainstream health services.

Further, Richard, the caregiver for his mother Harriet, also noted that sustained experiences of lacking access to formal health services led some African Americans to

avoid formal medical care even when they had access to government-sponsored or private insurance. Roger, also a caregiver for his mother, shared this perspective: “I think when you go so long without being able to go to a doctor, it’s hard to imagine that you now do have that access; you start thinking it’s not for you.” Similarly, Bridget explained how Linda, her mother, put off going to see a doctor for several months because she was used to caring for herself:

She actually had cancer pancreatic cancer. And she was doing pretty good, up until a year. Well maybe about ten months before her surgery. She stopped eating and just seemed to have less energy. Still, she kept saying she was fine and didn’t need a doctor. She had Medicare, but I think she still had that idea that she couldn’t afford to go. It was a few weeks before I finally convinced her to go. We didn’t know what was going on. Then we found out that she had three masses in her abdomen.

In this example, Bridget explains that a personal history of not having health coverage led her mother, and other African Americans, to avoid formal medical care even when it is available.

As participants pointed to the large numbers of African Americans who are financially excluded from the formal health system, they also noted that the majority of this population was able to access formal medical services. However, participants described the medical care that African Americans receive as frequently “lacking” (Charles, hospice patient), “poor” (Jane, hospice patient), or “unequal” (Kevin) in relation to other populations. Consistent with Haussmann et al.’s (2011) description of health care discrimination as a “perception of differential and negative treatment because

of one's membership in a particular demographic group" (p. 626; see also IOM, 2002), participants, such as Roger (caregiver), described feeling like "second-class patients." Participants recounted experiences where providers "talked down" to them, did not provide them with information about their health, or failed to consider their opinions or preferences regarding their care. Ruth, the caregiver for her husband, provided an example. She said:

I think we all know that many doctors don't treat everybody the same. I think it is especially with African American people, it's like we don't know any better, so the doctor just thinks they can do whatever they think is best and don't give you all the options.

Leroy described a similar perception in this way:

When they see a Black man like me, they ain't gonna tell you s--- unless they see them dollar signs. They think we don't know any better, so they just treat you like you nobody. That's what you are to them.

In this excerpt, Leroy tied his experiences of disrespect from health care providers to assumptions regarding a lack of knowledge about one's health status, which went hand-in-hand with concerns regarding mistreatment and/or exploitation.

Other participants shared Leroy's perspective that African American patients are at risk for mistreatment and exploitation by members of the health industry. For example, Kevin, a hospice patient, described his mother's experience: "My mother was in a nursing home through Medicaid for a time before we took her back in, and I can tell you that they weren't looking after her in the right way, not the same as the white folks." In addition to personal experiences, as Kevin described, others noted that these concerns

were also tied to the stories that others tell about their health experiences: Milton (caregiver) explained:

I think that's something you'll see or hear coming from Black families or a neighborhood like this one. It's like, 'So and so's doctor didn't give them the right medicine or this person didn't get an operation in time.' You start hearing who you should avoid and whatever.

Leroy told me he refused to consider a long-term care facility suggested by his doctor because he heard negative stories about the facility. "So he suggest this [Shady Pines] place, but I knew that was that one on the other side of [the highway]. I had already heard how they treat the Black patients there," he said.

Coupled with these concerns were worries that individuals in the health care system would financially take advantage of African American patients while providing inadequate care. As Carla told me, "Lots of the doctors or whoever else, they are only interested in doing things that keep they pockets full." Charles also shared this sentiment:

Charles: I thought for the longest that them doctors were just trying to keep me sick, you know, just keep me well enough that I'd just keep coming back, keeping getting billed.

Me: You really felt that way, Charles? Like they...

Charles: ...I did and I ain't the only one who says that type of thing. It wasn't until I got to meet Dr. [Johnson] that I felt somebody was looking out for me.

Noteworthy in Charles' response is his feeling that a health care provider being genuinely concerned for his wellbeing was an exception to his previous experiences.

Linking Structural Inequality to Disparities in Hospice Utilization

As our discussions shifted to disparities in hospice utilization, participants continually linked them to the structural inequalities that push many African Americans to the margins of the health system. Although hospice, particularly in the United States, began as a grassroots movement (Foster, 2007), it has increasingly become an integrated part of the mainstream health system (Chen et al., 2003; Connor, 2009). This integration has greatly improved the quality of and access to hospice services, but its connection to a health system that, in Robert's words, keeps many African Americans "at an arm's length" also has consequences for hospice use among this population. Therefore, from the perspective of study participants, to understand disparities in hospice use is to understand their connection to the structural inequalities described in the previous section.

For Robert, explaining hospice disparities started by acknowledging those African Americans who exist completely outside the formal health system:

It's like I said. You got a medical system that's set up to exclude certain people.

You gotta remember that hospice, it's part of that system. So you kind of expect it when you got so many people that don't have insurance. And don't have no money. And don't have no doctor. So, that doesn't explain all of it but that definitely, that is part of it, probably a big part of it.

Other participants shared Robert's perspective. Leroy said: "How the f--- you gonna get in there [hospice] if you ain't got no access to it [the health system]? You not. You're not getting in there." Further, participants suggested that the inability or unwillingness to seek medical treatment meant that some African American patients did not learn about their terminal diagnosis until it had reached an advanced stage. Milton explained:

If you have a good number of people who never see they or a doctor, then who knows what happens to them up to the point that they die. So there are people [that] probably die at home or whatever, and then you probably got some that finally go to a hospital or the emergency and die there. That's probably more people than y'all⁷ think.

Martin, a hospice patient, provided an example from his own experience. He explained that he first learned he had AIDS in an emergency room after passing out in a bus station while battling pneumonia:

I knew I hadn't been feeling right for a while, but what was I gonna do? I was working at [a restaurant] so I didn't, I couldn't see no doctors. By the time I found out [about the diagnosis], they was telling me that there wasn't too much to do.

Similarly, both Leroy and Charles told me that their heart conditions had worsened considerably during the years they were unable to seek formal medical treatment. As described in the previous section, others, like Bridget's mother Linda, deferred seeking treatment because they had grown accustomed to being financially unable to access formal health care, even when they had access to health insurance. As Bridget reiterated, "She was in her seventies, she had Medicare, but it [going to the doctor] was not something she had been able to do."

Although Martin, Leroy, and Charles, lived long enough to access hospice services, Carl told me how a close friend's mother, who did not have health coverage, had not sought treatment for persistent abdominal pain for several months before finally

⁷ As evident in Milton's quote (and several other instances in this manuscript), many of the participants associated me with and/or viewed me as an extension of Quest. I discuss (and problematize) this issue in Chapter 7.

going to a community hospital when she began vomiting blood. She was diagnosed with advanced cancer and died the next day (field notes, April 23, 2012). Thus, these late diagnoses that resulted from inaccess to consistent medical care did not provide time for hospice to be a viable option. Specifically, participants also suggested that a sudden terminal diagnoses did not provide enough time for patients and caregivers to consider their options. In such cases, participants felt that the default response from patients/caregivers and providers was to pursue aggressive treatment. As Keisha stated:

I think if you don't have a regular check-ups or whatever, and I can tell you that a lot of Black Americans don't, it can be pretty shocking to hear that somebody is likely to pass. I think that's another thing. I think your response is always going to be to try something, and the doctor is probably right there beside you saying, 'Yeah, let's go for it.'

Jack, a caregiver, noted that irregular access to medical care can also prevent African Americans from building trusting relationships with health care providers. "If you're not seeing a doctor regularly, how can you trust that this person is looking out for your best interest?," Jack said. As participants, like Kevin, argued, trust is a crucial feature of making decisions about hospice, as physicians must certify that patients are unlikely to benefit from further curative treatment. He stated:

It's one of those things where you are putting an immense amount of faith in that person. You have to trust that there is nothing better that can be done and that is your best option. That's a tough pill if you don't know that person well or have questions about them.

Later in our conversation, Kevin told me, “I think you have a lot of Black folks who wouldn’t have a doctor they trusted enough to allow that person to put them in hospice.”

In addition to limited access to the health system, participants again pointed to perceptions that African Americans do not receive equitable medical care as contributing to hospice disparities, as they tied these disparities to “poor treatment by doctors” (Jane, hospice patient) and concerns about being “taken advantage of” (Carl, caregiver, field notes, April 23, 2012). In describing this poor treatment, participants noted that physicians often failed to provide them with salient information or inquire about patient/caregivers’ feelings or preferences when making decisions about their/a loved one’s care. “The doctor never explained nothing to us, so we’re trying to get answers. He never asked any questions but then a person from hospice is there, so I’m just trying to figure it out,” Jack (caregiver) said. Roger discussed this further in describing his experience as a caregiver for his mother:

So Ma’s doctor, he keeps saying how things are gonna go and things could get better and whatever. Never asked what we thought or really said what’s happening. Always quick to dart out of the room before we could ask questions. We didn’t see her getting better but he’s just saying the same stuff and we just waiting. Then he comes back with wanting to talk about stopping treatment and starting hospice, and I’m like, ‘Okay, I’m supposed to trust you now?’ That’s a lot to ask a person.

Katherine narrated a similar experience from her perspective as a cancer patient:

When the [social worker from Quest], she came in to talk to me, when she came in to talk to me, I was very negative because they [her doctors] couldn’t tell me

what was wrong with me, and then here I see someone from hospice. So, then I knew something what was wrong with me. I was on my way out? That's what I said... the hospital, they couldn't tell me what was wrong with me, but then my oncologist just came in and told me, 'We're going to do this. We're going to do that.' That was the oncologist. It wasn't I guess the hospice. I don't know.

[inaudible], but it's not. It's a very scary thing, and then you go to your primary doctor who's been around with you wasn't sick, and he's just doing a premaintenance I call it, but then here I am.

As Katherine explained in this story, her physician had not discussed her diagnosis or prognosis prior to setting up an appointment with a Quest social worker to discuss hospice care. This failure made her angry and compromised her willingness to consider the hospice option. She went on to tell me that it was not until her son arrived from Houston and set up an appointment with a former classmate, an oncologist at another facility, that she was told about her options and decided to use Quest's services.

Coupled with experiences of poor treatment within the larger medical system are perceptions that hospice, itself, may be an avenue for further mistreatment or exploitation. As Carl recalled, "I can remember thinking, what's the real reason they are bringing this up. What are they selling me here?" (field notes, April 23, 2012). Julia, who is married to Carl, seconded his perspective by explaining that she and Carl had wondered whether hospice was a ploy to extend the monetary reimbursement for her mother's care (field notes, April 23, 2012). Roger's perspective mirrored Carl's, as he used nearly identical language to describe his initial response to the hospice option. He said: "I mean y'all [Quest representative] were nice and all, but there was like, what are

they selling me here?” There were also concerns regarding the quality of care patients would receive in hospice. Drawing on his mother’s mistreatment in a nursing facility, noted in the previous section, Kevin recounted his concerns upon learning that hospice care was most often provided in patients’ homes. He noted:

I can speak as a cancer patient, and I think a big thing is, are you going to get the same kind of care as everybody else? When I used to go get my treatments at [Cancer Center], everything was out there in the open. People would see how they was treating me. But when you start talking about care at home or in a facility, I worried about it.

These concerns regarding mistreatment were often reinforced by stories that circulated through families and communities about hospice. As Carla stated:

Well, I’m gonna tell you what I’d always been told about hospice. Hospice doesn’t care about the patient; they are only there for the patient to just let them die and not take care of them.

The stories and perspectives shared in this section demonstrate that participants connect disparities in hospice utilization to inequalities in the larger structure of the health system. The following section describes how participants equate hospice and its underlying philosophy as exclusionary.

Hospice as an Incompatible Framework of Care

It is well documented that those who identify as African American do not constitute a homogenous group (Dillon et al., 2012; IOM, 2002), a perspective that participants in this study shared. A typical response was offered by Pearl, the primary caregiver for George (her husband), who said:

It's hard to really speak for a large group of people because people come from different places and have unique experiences. So that makes it hard, but I think there are some general things about being Black that pertain to hospice and could be helpful.

Although participants noted that generalizing across the broad population of individuals who consider themselves African American was a potentially problematic endeavor, they did highlight features of the hospice philosophy that were possibly incompatible with values that they associate with African American culture. Thus, in addition to shared experiences of discrimination in the health system, patients and caregivers argued that the underlying philosophy of hospice care was inconsistent with values and practices that they associated with African American cultural traditions.

In particular, they echoed participant narratives in previous studies by noting that acknowledging impending death and discontinuing curative treatment can be perceived as “giving up” on oneself or a loved one in many African American families (e.g., Born et al., 2004; Scharlach et al., 2006; Taxis, 2006). Some tied the reluctance to accept the inevitability of death or forgo curative treatment as tied to Christian spirituality, principally the beliefs that “only God knows when it is time” (Mandy, patient) and “if you stop treatment, you are saying ‘no’ to the means God sent you to get better” (Lisa). For others, it was tied to a “fighting spirit” (Richard) passed on from previous generations. “As Black people, we have had to fight for a lot things, so I think we see sickness the same way,” Milton stated.

In linking these cultural values/practices to hospice, the participants questioned the necessity of making a choice between curative treatment and comfort care, as

necessitated by the Medicare Hospice Benefit and other reimbursement entities (see United States Congress, 1996). They noted that this either-or choice was difficult for some African Americans to accept, even if they would benefit from hospice services.

Richard explained:

One of the things I never understood is why does a person have to choose if they can go to a hospice or keeping getting better. I think one thing you'll see is among Black folks that there is a strong will, I mean a real strong feeling that you can't be giving up the fight. You need to fight until the end. So that hung us up with my mother and we got to a point where we were able to be with hospice but still getting, her still getting the chemo. I mean, why should you have to choose to be taken care of or to try to get better?

Consistent with Richard's articulation, participants suggested that a greater number of African Americans would access hospice services if they were allowed to continue curative treatment while receiving the same level of care from hospice organizations like Quest.

In addition to the potential incompatibility of accepting a terminal diagnosis and discontinuing curative treatment, participants also highlighted the incongruence between the hospice philosophy and the cultural emphasis on caring for sick/dying loved ones within African American family systems. According to several participants, many African Americans may see the help that hospice provides as incompatible with this tradition. Belle explained that there was a notion among some African Americans that utilizing hospice services was akin to abdicating an important familial responsibility. She said:

I think a lot of the African Americans in the community, they need to know [more about hospice]... They don't have no access or knowledge of it. They have heard about it and the first thing they think because they come in and take over, you know, like it means the family doesn't want to take care of them. They just want it over and gone. That's all they hear, is the bad.

Bridget told me that in addition to feeling responsible for caring for family member near the end of life, some caregivers were concerned about what other African Americans would think about them if they invited hospice providers into their home. She illustrated this point by telling me about a close friend who hid the fact that her father was receiving hospice care from her neighbors. She explained:

People start seeing these people coming in and out the house, you know, wearing nurses' clothes, so her neighbors start asking about. [laughter] Do you know what she did? [She] tells them that it is her cousin, who is a nurse, just coming to visit. That's how deep it goes. [laughter] She was worried they would think she was trying to push her dad out the door.

For study participants, the disconnect between the hospice philosophy and these cultural values represented yet another form of structural inequality within the U.S. health system. They suggested that hospice, itself, is a system of care that is not designed for African Americans; it is based in the needs, cultural idioms, and preferences of white patients and their families. "It's not meant for us, as Black people. If it was, you wouldn't see these kinds of disconnects. You wouldn't have the same kinds of questions" (Jason, caregiver, field notes, April 10, 2012).

Even as participants noted the potential incongruences between the hospice philosophy and African American values, they suggested that, in practice, hospice was not inherently incompatible with the needs, values, and preferences of many African Americans. From their perspective, utilizing hospice services did not mean that they were giving up hope that their loved one could recover and viewed the care that hospice provided as a mechanism to provide the best care possible to their family members and close friends. They argued, however, that perceptions of these incompatibilities persisted because health care providers, namely physicians and hospice social workers, who were often patients' and caregivers' first point of contact with hospice, were unaware of or did not recognize the potential for these incongruences.

Pointing out that, in their experiences, the majority of these physicians and social workers were not African American, participants noted that these individuals were often unable to see beyond their own perspectives when explaining what hospice is and the services that are available. Pearl explained:

I remember when George's doctor first started talking about hospice. He was a young, for a doctor, white guy, and I can remember his saying something like, 'There's a point where you have to accept that the end is near, that he's not getting better. If this was my family, I would be at that point...It made me so mad because it was just like he wasn't understanding where I was coming from at all. My family is not like his family...We eventually got past that, but there's probably lots of people who couldn't do that.

Keisha made a similar point:

I don't think most doctors or even the people that come from Quest to talk with us really understand all that goes into deciding about hospice, particularly when I Black person. They don't know the baggage that comes with it, the things you heard about, or the perceptions you might have to deal with.

She went on to tell me, "If they would just listen to those things and understand, that would go a long way and make a big difference." Keisha's assertion was supported by stories like those shared by Carl and Julia. They explained that Betsy's (Julia's mother) doctor spoke with them about hospice on "at least three occasions" before they felt it was something they could consider (field notes, April 23, 2012). They told me that her physician kept highlighting all of the "thing hospice would come in and do for us" while Carl and Julia were unwilling to "give up control of her care" (field notes, April 23, 2012). It was not until they realized that hospice would still allow them "be in control of her care" and could help them "offer the best care possible" that Julia and Carl decided to meet with a representative from Quest (field notes, April 23, 2012).

Carla provided a similar example as she described the "turning point" in her decision to enroll her mother in hospice: "It was when the [Kelly], the social worker, said I could have as much or as little help caring for her as I wanted. That assured me that I wouldn't be cast aside or not be a part of her care." Although participants noted that the best way to address hospice disparities would be to change policies that limit access to those who agree to forgo curative treatment, they suggested that concerns about the compatibility between the hospice philosophy and African American values could potentially be alleviated, to a degree, by providers being willing to consider how patients and caregivers perceived hospice services.

Discussion

This chapter follows previous culture-centered studies in depicting the alternative rationalities of health disparities that emerge when scholars engage the voices of marginalized populations and introduce them to the mainstream discourses of health communication (Basu, 2011; Dutta, 2008, 2012). By listening to the perspectives of African American hospice patients and caregivers, alternative understandings of disparities in hospice utilization emerge, understandings that link these disparities to the *structural violence* (Farmer, 1999, 2003) perpetuated against African Americans in the mainstream health system. These perspectives resist the dominant logic that positions hospice disparities as disconnected from persistent inequalities in the larger health system. Even as scholars identify factors such as mistrust of health care providers, fears about mistreatment, and preferences for aggressive care (e.g., Bullock, 2011; Enguidanos et al., 2011; Johnson et al., 2009), the mainstream, interventionist logic underlying these studies presents them as individual-level, cultural barriers that can be overcome by making African Americans the targets of persuasive messages. In highlighting the need for structural reforms that promote equal access to high quality care and reformulate policies to meet the needs of all patients, participants offer an alternative rationality for promoting health equity in the realm of end-of-life care.

The *culturally sensitive* logic (see Dutta & Basu, 2011) that disparities in hospice utilization can be overcome by providing accurate, culturally-relevant information assumes that individuals have access to the mainstream health system and need only make an informed decision about their care options. Such an approach further assumes that patients are aware of their clinical condition, treated with respect, and are willing to

place their trust in the physician who makes a hospice referral. It does not assume a system where one in five African Americans is without health insurance coverage and/or lack regular access to health services (DeNavas-Walt, Proctor, & Smith, 2011; U. S. Department of Health and Human Services, 2012). It does not assume a system where physicians rate their African American patients as less educated, less intelligent, more likely to abuse drugs and alcohol, and less likely to follow physicians' treatment recommendations (van Ryn & Burke 2000; see also Peek, Odoms-Young, Quinn, Gorawara-Bhat, Wilson, & Chin, 2010). It does not assume a system where racial bias may influence the treatment recommendations physicians provide (e.g., Green et al., 2007) or one where experiences of discrimination reduce patients' willingness to seek medical care (Hausmann, Jeong, Bost, & Ibrahim, 2008). In short, the culturally sensitive logic that underlies message-based recommendations to addressing disparities in hospice utilization assumes a health system that, in the experience of many African Americans, does not exist. The framing of hospice disparities as solely the result of individual-level behaviors or knowledge deficiencies serves to leave unquestioned the oppressive features of the health system and perpetuate an unhealthy status quo (Dutta & Basu, 2011).

It is against this backdrop that the CCA emerges as a framework, which acknowledges that, in the case of health inequities, "it is neither nature nor pure individual will that is at fault; but rather historically given (and often economically driven) processes and forces that conspire to constrain individual agency" (Farmer, 1999, p. 23). Aligned with the voices of participants in this study, the CCA suggests that meaningful efforts to address hospice disparities (or any other health problem) must engage the structural issues that (re)produce health inequalities in the first place. This is

not to discount the potential value of increasing awareness and addressing misconceptions about hospice; it is only to suggest that such efforts must (at the very least) be balanced by structural interventions that promote access to health services and seek to eliminate discrimination by health care providers. The results of this study call for continued interrogation of the “growing influence of the market ideology and corporate structures that are shaping medicine and health care delivery” (Rylko-Bauer & Farmer, 2002, p. 476). In particular, there is a dire need to examine how the market-based logic that positions access to medical services as a “commodity” and leaves millions of Americans, particularly racial/ethnic minorities, without health insurance plays out in the lived experiences of these individuals. As media members and politicians debate the merits of a public or private U.S. health system, individuals, like the ones who took part in this study, are left to negotiate the realities of lacking access to formal health care. Studies like this one foist these experiences to the forefront of discourses surrounding the health system and persistent inequities in access to medical services. Such studies also have the opportunity to encourage policymakers to push forward reform efforts that reach beyond the Patient Protection and Affordable Care Act⁸, which will leave an estimated 23 million Americans uninsured (Coughlin, Long, Sheen, & Tolbert, 2012) and racial/ethnic minorities at continually greater risk to be without health coverage (Clemans-Cope, Kenney, Buettgens, Carroll, & Blavin, 2012).

⁸ The Patient Protection and Affordable Care Act, often abbreviated as the Affordable Care Act, is U.S. health care reform legislation that was signed into law by President Barack Obama in March 2010. It is considered the most significant legislative overhaul of the health care system since the expansion of the Social Security Act in the 1960s. Among the primary goals of the law is to decrease the number of uninsured Americans by requiring most individuals to secure health insurance, expanding government-sponsored health coverage (i.e., Medicare and Medicaid), and making private insurance more affordable (see HealthCare.gov).

Specific to hospice provision, this study foregrounds the need to revisit reimbursement policies that limit hospice services. As explained in the first chapter, the Medicare Hospice Benefit stipulates that patients discontinue curative treatment in order to qualify for hospice care (United States Congress, 1996). As Fishman and colleagues argue, this requirements forces patients and their loved ones “to make a ‘terrible choice’ between continued treatment and hospice services” (Fishman, O’Dwyer, Lu, Henderson, Asch, & Casarett, 2009, p. 690; see also Casarett Fishman, Lu, O’Dwyer, Barg, & Naylor, & Asch,2009). Quite like Fishman et al.’s (2009) findings, the results of this study suggest that this criterion is incompatible with the values of many African Americans and may limit hospice use among this population (as well as others). Although the hospice philosophy suggests that no patient or family be turned away because of financial reasons and hospice organizations provide millions of dollars in charitable care (see Connor, 2009), as evidenced by the findings of this study, the restriction that patients forgo curative treatment is a significant part of the discourse surrounding hospice care. Thus, although the Medicare Hospice Benefit was enacted to provide access to high quality end-of-life care for all Americans, it seems that the policy may actually contribute to disparities in hospice utilization. Rather than forcing patients to abstain from treatment in order to receive hospice services, something African Americans may be particularly unwilling to consider, it seems that hospice use could be more equitable if eligibility criteria focused more directly on patients need (e.g., for pain and symptom management or psychological/spiritual counseling, see Aldridge-Carlson, Barry, Cherlin, McCorkle, & Bradley, 2012; Fishman et al., 2009). The narratives listed in this chapter also suggest a need for an expansion of concurrent care, a treatment option that integrates palliative and

curative services (Aldridge-Carlson et al., 2012), as well as a greater integration of outpatient/in-home palliative services for seriously ill patients across the continuum of care (see Smith et al., 2012).

In addition to expanding the availability of health coverage and revisiting hospice reimbursement policies, it is also imperative that efforts are made to address the racial discrimination that leads to inequitable care across the spectrum of the formal health system (Peek et al., 2010). There is evidence to suggest that medical education modules that focus on discrimination in the health system may help students identify and address their own racial biases (Peek et al., 2010; Teal, Shada, Gill, Thompson, Frugé, Villarreal, & Haidet, 2010). Others suggest that increasing the racial/ethnic diversity of health care providers could serve to diminish the potential for discrimination. Cohen, Gabriel, and Terrell (2002) argue, for example, that greater diversity in the medical workforce would promote greater cultural competence, which they define as "the knowledge, skills, attitudes, and behavior required of a practitioner to provide optimal health care services to persons from a wide range of cultural and ethnic backgrounds" (p. 92). In advancing their argument, the authors focus on the value of diversity in educational settings where future providers are trained. They write:

Health care professionals cannot become culturally competent solely by reading textbooks and listening to lectures. They must be educated in environments that are emblematic of the diverse society they will be called upon to serve. The logic here is analogous to that upholding the value of diversity in all aspects of

higher education...Only by encountering and interacting with individuals from a variety of racial and ethnic backgrounds can students transcend their own viewpoints and see them through the eyes of others. (p. 92)

Additionally, participants in this study suggest a need for providers to see beyond their own professional/cultural frameworks in order to appreciate alternative conceptions of hospice. Following Goldsmith, Wittenberg-Lyles, Ragan, and Nussbaum (2011), this process must move beyond the training manual approach where providers are taught to interact with African Americans (or other racial/ethnic minority) patients in particular ways. Instead, it may be most beneficial for providers to embrace an approach akin to Charon's (2006, 2009) "narrative medicine," which emphasizes the meaning that patients/caregivers assign to health experiences within the larger life story. As Charon (2009) describes, narrative medicine is a clinical discipline that entails an "effort to make audible to clinicians what patients try so hard to tell them and to make visible through imaginative attention that plight in which patients' illnesses cast them" (p. 119). Such efforts may go a long way toward helping physicians make sense how patients and their loved ones, including those who are African American, understand their illness and their treatment options (including hospice). For example, rather than explaining the decision he or she would make in a similar circumstance, as the physician did in Pearl's story, providers should begin by listening to the way patients/caregivers make sense of their current situation as well as their understanding of hospice in relation to their cultural frameworks and personal preferences. A narrative medicine approach may also help providers understand the relational consequences of utilizing hospice services. Stories like Bridget's friend, who hid the fact that her father was in hospice from her neighbors,

indicates that the "stakes" of utilizing hospice services may be different for particular patients/caregivers and, thus, may require different kinds of information as well as increased levels of social support (Ragan et al., 2008). By fostering dialogue and privileging patients' accounts, narrative approaches may help providers better understand patients' wishes and meet their expectations for care.

Conclusion

Grounded in the logic of cultural sensitivity, previous studies have positioned hospice disparities as a matter of knowledge deficiency and absent communication. The results of this chapter suggest that a health care system that keeps many African Americans "at an arm's length" (Robert, caregiver) makes it difficult for patients and their loved ones to embrace hospice care. Given these structural constraints and the potential cultural incompatibilities of hospice care highlighted by participants in this section, it seems reasonable to question how these individuals ultimately chose to be a part of the hospice system. In response to this study's second research question, the following chapter examines the communicative process through which patients and caregivers made decisions to use hospice services.

Chapter 4: Patients and Caregivers' Decision-Making Narratives

Having described how inequality in the structure of the United States' health system contributes to disparities in hospice utilization among African Americans, this chapter explores how patients and caregivers work within this structure to make decisions about using hospice services. Thus, this chapter engages with the study's second research question: *RQ2: How do African American patients and caregivers describe their decisions to use hospice care?* Drawing from the constructivist grounded theory approach that guided my data analysis (Charmaz, 2006); the results presented in this chapter proceed from a "case-centered" theory building perspective typical of narrative analysis (Riessman, 2008). More specifically, I focused on participants' accounts of their initial decision to use hospice services in order to identify prominent themes in the individual stories and then used a constant comparative method to characterize recurrent themes that cut across the narratives (Vanderford & Smith, 1996). This analysis produced three primary themes: an acceptable definition of hospice, the importance of caring for others, and placing trust in close family and friends. Taken together, these themes highlight the communicative processes through which patients and caregivers work within the health system to make hospice decisions that meet their contextual needs and are consistent with their cultural values. The following sections discuss each of these themes in detail.

Constructing an Acceptable Definition of Hospice

The first major theme that emerged from participants' decision-making stories was the importance of constructing an acceptable definition of hospice. In describing these constructions, patients and caregivers noted how their definitions related to their understanding of the formal, medically sanctioned definition of hospice care as it was communicated by health care providers. From an institutional perspective, participants understood hospice based on the type of patients it was designed to serve and the gatekeepers (i.e., physicians and hospice providers) who regulate hospice access. Pearl explained:

The way I understand it, hospice is the care you get when you know you coming up on the end. That's how it was for us. George finally reached a point where he was not getting better. That's when hospice is supposed to come in, and they did with us. We didn't want him to go through any more pain, so that's like what hospice can do. Once the doctor gives you the 'okay,' [Quest] help take care of you, keep you comfy, so that you and your family can enjoy your last days.

As participants reached a point where hospice became an option for them or their loved ones, they were forced to consider whether this form of care met their contextual needs, and, more importantly, fit with their cultural/familial values. As Jack (caregiver) explained that deciding to use hospice services for most participants was a process of "accepting what hospice is and deciding that you and your family were the right kind of people for it." Consider the following narrative shared by Milton (caregiver):

It took us a while but the biggest thing for me, and I think [Keisha] would agree,

for us as a family was that we just had to wrap our mind around what hospice is. We had been praying for so long that she would get better... asking God to heal her. We sort of had this family meeting where we...we stepped back and said we have to trust that God is putting us in this position for a reason...cause that's a big thing for us, we felt like she needed a lot of help and that [Quest] could control her pain. She had been through a lot and we felt like God wanted her to ease her way out of this life [laughs]. So we went back to Dr. [Jones] and said we wanted him to arrange that meeting with [Quest].

Milton began his story by noting that the “biggest” thing for his family when making the decision to use hospice services was to understand the modalities of this form of care. He went on to explain that the ultimate decision came when the family was able to align the institutional definition of hospice with their Christian faith and the belief that these services would benefit their aunt as she neared the end of life. The majority of patients and caregivers (n = 22) shared similar decision-making stories, in which they came to understand the institutional definition of hospice and decided that it fit with their needs/values.

Others like Charles (hospice patient), Belle (caregiver), and Kevin (hospice patient), were unwilling to accept the institutional definition of hospice. Although these participants felt that they and/or their loved ones would benefit from hospice services, they viewed certain aspects of the mainstream definition as incompatible with their cultural/familial values, particularly the requirement that they accept the patient's terminal diagnosis and prepare for the end of life. Highlighting an emphasis on “persevering” (Geraldine, caregiver) and not “giving up the fight” (Leroy, patient), which

they associated with African American values, these participants described the need to develop *alternative definitions* of hospice in order to access the benefits of these services on their own terms. They described this as a process of assigning new meanings to hospice while engaging in actions that would be endorsed by the system's gatekeepers (i.e., physicians and hospice providers).

For Geraldine and her mother Betty (hospice patient), a hospice patient with lung disease, their decision to use hospice services was dependent on a shift from understanding hospice as a way to prepare for the end of life to viewing it as a way to receive high quality care while preparing for future curative treatment. Geraldine explained this during our interview. She said:

It was probably four, five months ago that she [Betty] had a last treatment and she was just so beaten down, like couldn't get out of bed and eating nothing...So she was in rough shape when Dr. [Cook] brings up hospice. He explained it but my brother Jimmy and I, we just couldn't get with what he was saying. We wasn't just gonna give up, that's not our way.

After taking her mother for another opinion, the second physician also suggested that the family consider hospice.

It was at this point that Geraldine and her family began considering looking at hospice in a new way. "The things he was saying sounded good...like the in-home visits, the pain meds, and the pastor who would come out," she explained. After sitting down and talking it over, a process Geraldine described as taking a "second look at what hospice could be," they decided that they would use hospice to build up Betty's strength until she was ready for another treatment.

In addition to Geraldine and Betty, three other participants shared the conception of hospice as a way to prepare for future treatment. Belle, the caregiver for her father Curtis, noted:

When I took my father to the physician's office and the cancer doctor that Monday, he suggested to me he was really weak and that he looked too frail. If I could get some weight on him and build up his body then he would think about starting chemotherapy again. But in the meantime, I checked into Quest to see what options were available, and to get some type of assistance...To build his strength and get some help in there, so he would be ready for treatment.

She added: "I know I did right. From my standpoint, as part of my cultural upbringing, I was taught that you don't give up, and hospice or not, that's what I did for my dad. It's all God's timing anyway."

For three other participants, a belief in "God's timing" was central to a second alternative definition of hospice that emerged in their decision-making stories. From the perspective of these participants, hospice was a means of extending life beyond what would be possible by pursuing curative treatment. A prevailing aspect of stories that highlighted this alternative definition of hospice was the belief that God was "in control" of their health and, thus, they were not dependent on medical care. Additionally, many of these stories highlighted a skepticism toward the mainstream health system, reflective of the well-documented mistrust of the health system among African Americans (e.g., IOM, 2002; Peek et al., 2010). In reflecting on his decision to obtain services from Quest, Charles, a hospice patient with heart disease, explained that he viewed hospice as a way

to meet his basic needs while avoiding the treatments he felt were making his condition worse. He told me:

God helping me the most. He helping me the most...He is the doctor. He call all the shots. I don't care what no doctor said, no nurse, it's His call whether you live or die. What time, it's His time, there's nobody else time. They say you gonna be here tomorrow or maybe not but it's still His time. It's still His time. He gonna call that shot... So I'm hoping I can get out of here and get back where I can go places, do things, you know, walk around without the walker or the wheelchair. I just don't understand, why it taking so long...Whatever happens I know I'm doing better than I was with the doctor. I wouldn't be here now if I had stuck with the doctor.

The feeling that hospice would extend life by offering an escape from debilitating treatments was shared by Jane (hospice patient). Jane's physician said he could certify her for hospice care but felt that there was "chance" (Jane) she would respond to further treatment. From her perspective, she could not trust that her physician had her best interest in mind and was fearful that he was being optimistic about her treatment in an effort to "take advantage" (Jane) of her. In describing her decision to use hospice services, Jane said:

The doctor told me I had, might only have 5, 6 months to live, I wanted to know what my options were. So we started talking about different treatments, but I remembered my friend Kathy who had the same type of cancer and how she suffered through them treatments. Her daughter always said that it was the treatments that killed her...I thought, well these doctors don't always know

what's best and only God knows when I'm gonna die. So I asked what else we could do and we started talking about hospice. I felt like I would do better with that. Like I said, the doctors don't know when you're dying anyway and I don't want treatments that are just going to beat me down while they're writing checks. As evident in her story, Jane's perception of the futility of further treatment was based on both a general skepticism toward the medical system and the personal experience of a close friend. She decided to enroll in hospice but did so on her own terms (i.e., with the belief that hospice was a way to extend her life beyond what would be possible by continuing cancer treatment).

Even as participants described alternative conceptions of hospice, they highlighted the necessity of an endorsement from a physician in order for them to be considered "legitimate" hospice patients. Belle's experience, as described above, was unique in the sense that she and her father's physician seemed to develop an understanding of hospice as preparation for treatment through "provider-caregiver collusion" (see Ellis, 2000). In all other cases, patients described the need to work within the system in order to gain access to hospice care. For Jane, this meant that she had to "go along" with the way her physician (and eventually the hospice social worker) described hospice:

I told him [her physician] that I knew what was happening. That meant I told him I knew what he thought was happening, but I knew I just didn't want to continue with all those treatments...So you gotta know what they expect you to say and you just go along...If I had said I was entering hospice to live longer, he would have tried to talk me out of it or said I didn't understand what it was.

Similar to Jane's story, other patients and caregivers described the need to overtly express agreement with the institutional definition of hospice to physicians and hospice providers while maintaining the alternative definition for themselves or among their families. As Geraldine explained, the need to hide these alternative definitions of hospice was necessitated by the gatekeeper status of physicians and hospice providers: "If you want the meds, if you want them to come out to the house, you want the wheelchair, whatever, you have to do it on their terms." Although access is also tied to physical markers of decline, which are outside of patient/caregivers' control, they highlighted their ability to communicate in ways that are consistent with the institutional understanding of hospice as a necessary part of obtaining access to care services. This perception was shared Kevin, a cancer patient, who viewed hospice as way to prepare for further treatment. He told me:

They [Quest] send the social worker out here to meet me and she says things like, 'How are you coping?', you know, acting like I'm approaching the end. I just tell her, 'It's tough, but I'm doing okay.' The whole time I'm thinking, I am gonna be doing better soon, when I can go home and have somebody there to help me.

Once I'm better though, I'll be getting them up out here and go back to my chemotherapy. You can't say that though cause you don't want things to go away.

Kevin drew attention to the perceived need to hide alternative hospice definitions because of the fear that he would be denied services that he could benefit from. He also acknowledged that there was some "truth" to what the doctors and hospice providers were telling him. "I know there's a chance that things could happen the way they say, that I won't be here much longer. I'm not just gonna accept that though. I ain't giving up

hope,” he explained. Because physicians and hospice providers, given their status within the larger health system, have the authority to dictate who does and does not have access to hospice services, patients/caregivers who did not accept the perceived institutional definition felt the need to hide their alternative conceptions in order to gain access to needed care.

The Importance of Caring for Others

In addition to emphasizing the need for an acceptable definition of hospice, the majority of participants’ (n = 25) also highlighted the potential for hospice services to help them care for others as a salient feature in their decision-making stories. Regardless of how they defined hospice, both caregivers and patients often spoke of the personal benefits that hospice offered. In telling stories about the initial decision to use Quest’s services, however, their narratives were decidedly other-focused. That is, they described the decision to use hospice as based on their perception of the benefits that their loved ones would receive from Quest. For Jasmine (caregiver), focusing on the benefits that hospice could provide Martin, her brother, was tied to an emphasis on personally caring for sick and dying family members that she associated with African American culture. She explained:

It’s a big part of who, of us as Black people. We take care of our own; that’s what we taught to do. My momma and aunts and uncles, we always talk about caring for our people when they need it. For me, when we start talking about hospice, I see it as the best way to do that. [Martin] wasn’t getting on too well, but I knew with [Quest’s] help, I’d be able to do what he needed.

The link between choosing to access hospice services and the cultural importance of caring for sick and dying loved ones was common among other caregivers as well.

Keisha (caregiver), for example, described this cultural value as essential to understanding African American families, particularly how they respond to serious illness. Other participants also shared Jasmine's description of caring for loved ones as a tradition that is passed to younger family members from members of the previous generation. Milton (caregiver) stated: "You can't escape that. You learn from the time you young that it's your job to look out for your family when they are ill."

As they described their decisions to use hospice services, and how these decisions fit with the cultural tradition of caring for sick family members, caregivers, in particular, emphasized that enrolling in hospice would allow patients to be cared for at home. Note, for instance, Pearl's description of caring for her husband George:

I really wanted to be the one who was responsible for his care. I wanted him to be at home...because I could be sure I knew what was happening all the time. When you in the hospital or wherever, you have restricted times, you know? At my house, I would be able to ensure that [George] was treated good because my eyes were on everything, everybody at all times.

Other caregivers, like Pearl, suggested that a central feature of their decision to use Quest's services was the chance to shift the site of care from an institutional setting (i.e., hospital, skilled nursing facility) to the home. In particular, they noted how this shift would allow them an increased level of control over their loved one's care. Jack (caregiver) said:

I never feel like myself at a hospital. You're just sort at the mercy of what they want to do. But when we shifted to my house with [Quest], I knew things would

change. That's my fortress, my domain, and things are not going to happen unless I say it's okay.

The opportunity to oversee their loved one's care was particularly salient for caregivers in this study, as many of them indicated that being African American would put their loved ones at greater risk for discrimination and inferior care (a point described in the previous section; see also IOM, 2002; Peek et al., 2010). Bridget (caregiver) explained:

I think there's always a concern, when you an African American family that doctors or whoever won't treat you the same. Of what they actually do. So you get this different view of health care, what you can expect. And even though some people are just not comfortable with others coming in their homes. Cause not everyone is not trusting of someone of coming in their home. With hospice though, you got more say over things because you there all the time. Well, at least somebody else is there...So I think you can feel better about what's gonna happen.

By moving care for their family members into the home, caregivers felt they would be able to oversee the hospice team members and ensure that they were satisfied with the services that were being provided.

Many caregivers' also noted how hospice team members could assist them in providing a level of care that would have been impossible on their own. Ruth (caregiver), for example, told me how David's (her husband) lung disease caused him extreme pain. Although she wanted to care for him at home, she was concerned that she would be unable to control his pain with oral medication. Thus, the knowledge that Quest could provide "the highest level of pain medication" was a particularly salient factor for Ruth.

Similarly, Keisha and Milton (caregivers) explained how pain management was an important feature of their hospice decision:

Keisha: We wasn't sure at this point. We had agreed to let them come out and see her but didn't make no promises about letting them come in. So she [the hospice nurse] starts talking about pain meds and whatever...

Milton: ...We didn't know what we thought about that. She had been in that rehabilitation facility before. We mentioned that I think...

Me: ...Yeah, you did and uh...

Keisha: ...We had felt like she was getting too much pain meds. She was just sleeping so long.

Milton: So we start telling the nurse that we wouldn't want that. We want her to be awake as much as she could. I mean that's what she wanted too.

Keisha: We told her that if we went with them [Quest], we would make sure that she wasn't getting too much medication. And the nurse...she says we wouldn't have to worry about that. So that was a big deal for us.

Noteworthy in this instance is the link between providing high quality care (i.e., appropriate pain medication) and the potential for increased control for family members.

In addition to pain medication, caregivers' stories highlighted other features of hospice care as central to their initial decision to use Quest's services. The most frequently cited reasons included access to medical supplies. Caregivers described how access to hospital beds, shower chairs, walkers, and ramps that covered stairs in their homes would improve patients' quality of life. Caregivers also pointed to the availability of professional care training from hospice employees. Bridget, for example, told me how

her husband's face "lit up" when he heard from a friend of theirs that hospice services often included care training for family members. She went on to explain that "he had been so afraid he was going to hurt her [Bridget's mother] when moving her around." Finally, caregivers, like Jasmine, also noted the benefit of having a hospice team member available to provide care in a way that helped patients to maintain their dignity. Jasmine noted:

[Martin]'s my brother, so there are some things that he just doesn't want me, he doesn't want me doing certain things. Like before y'all [Quest] started coming out, I would have to give him a bath. Nobody wants they sister doing that. So when I heard that you [Quest] had people who would do that, I thought that would be a good thing.

It is perhaps unsurprising that caregivers' hospice decision-making narratives emphasized their perception of how Quest's services would benefit sick and dying family members. In listening to patients' stories, as well, it was clear that their hospice decisions also focused on meeting the needs of others. For participants like Mandy, a hospice patient with cancer, the decision to enter hospice involved a balance of caring for herself while caring for her loved ones. From Mandy's perspective, Quest would provide high quality care at home while allowing her daughter to take a primary role in the caregiving process. She explained:

I knew I wanted to be at home, but I needed a lot of help. The kind of things that my daughter or her boyfriend weren't going to be able to do. They don't know nothing about medicines or helping somebody get around. But I didn't want to be

in no nursing home, so I told my daughter, 'We need to go with them people from Quest, so I can go home.'

Mandy's emphasis on considering her daughter's needs became clearer in her response to a follow-up question:

Me: So the biggest thing for you was to make sure you could get the best care but be at home?

Mandy: You could say it like that but I was mostly, I mean I was wanting my daughter to be a part of it. She was taking it hard when I'd been so sick, like, 'Momma, I want to take care of you but you needing so much help.' She was taking it pretty hard so the way I had understood hospice was that she would be feeling like she was taking care of me but would be getting help...That seemed like the best thing.

As she described above, the "best thing" about hospice was that it allowed her daughter to take an active role in Mandy's care, an important priority for both of them.

Unlike Mandy, Leroy was unsure if it was the best option for him when he made the initial decision to access hospice a few years before our interview. From his perspective, however, the more important priority was to ease the burden that caring for him would place on his daughter. He argued:

My girl, she would go to the end of the f----- world to care for me, if I would let her. She told me so all the time. I couldn't make her do that. She has a life, a real good job. I'm so proud of her...and I couldn't ask her to set that off to the side for me...I'm her daddy, my job is to help her succeed.

As Leroy described his decision, it was clear that his priority was fulfilling his responsibilities as a father. Other patients shared this perspective as well. In describing his mother's decision to enter hospice, for example, Richard (caregiver) noted how she maintained a focus on "taking care" of him and his siblings. At the beginning of the following excerpt, he explains that he was surprised when he arrived at the hospital and found out his mother had already decided that she wanted to enter hospice:

I tried to explain that there might be other options, but she said that hospice care was what she wanted, and we wanted to follow her wishes... We found out later from her friend that Mom had been worried about how hard it would be to take care of her. She wanted us to enjoy her last days as best we could... She had always taken care of us and I guess hospice was just another way for her to do that.

Similar to Leroy's story, Richard's mother, even when she was very sick, focused on her maternal role as a caregiver.

As apparent in this section, participants' decision-making narratives emphasized hospice care as a mechanism to meet the needs of their loved ones. Through these stories, patients and caregivers pointed to increased control, access to quality health services, and easing the caregiving burden as central features of their decisions to use Quest's services.

Placing Trust in Family and Friends

The third primary theme that emerged across patients and caregivers' decision-making narratives was placing trust in family members and close friends when choosing to access hospice care. This theme played a prominent role in 21 participants' stories. Although the specific role of family members and friends varied across the stories, they played an important role in the initial decision to use Quest's services in all cases. Once

again, participants often juxtaposed the trust placed in family and friends with a skepticism for or mistrust of health care providers, particularly physicians, regarding their recommendation that the patient/family consider hospice. For example, Roger (caregiver) explained that his mother's oncologist first discussed hospice with Roger and then scheduled a time for Roger to meet with a Quest representative. When I asked if this initial meeting influenced his decision to use hospice services to care for his mother, Roger replied:

Nope. I can't say that it was. I mean y'all [Quest] were nice and all, but there was like, what are they selling me here? I left and called my mother's pastor...he tells me that he is familiar with hospice and thinks they did good work. That's all what I needed there to make up my mind.

After his conversation with the pastor, Roger called Quest to arrange hospice care for his mother. Later in our interview, he expounded on his decision to discuss hospice with his mother's pastor. He told me:

That's a person I trust. I don't question that he looking out for Ma's best interest. I didn't feel that way about the doctor, well not all the time. It always seemed like he was keeping some things from us or acting like we couldn't understand certain things. I didn't like that.

In addition to providing a trusted recommendation regarding the quality of hospice care, Roger noted that the pastor was able to assure him that hospice was not inconsistent with the teachings of his mother's church, another important consideration for him and his mother. Thus, from his perspective, going outside the formal health system allowed him to gain needed information about hospice from a trusted person.

Other participants' stories followed a similar pattern. Rose, a hospice patient with heart disease, told me she was concerned about the level of care she would receive from Quest after discussing this option with her doctor, as she had been displeased with this physician's care (field notes, March 22, 2012). A close friend who accompanied Rose to her medical appointments knew a woman whose mother had died under hospice care a few months before. Rose's friend invited the woman to come to Rose's home to discuss her hospice experience. Through this conversation, Rose was able to learn more about the medical supplies she would have access to as well as the spiritual care services that Quest provided. These features were important to Rose, but she had not discussed them with her doctor. After this conversation, Rose decided that she would benefit from hospice.

Katherine, a hospice patient with cancer, narrated a similar story. As discussed in the previous chapter, she was displeased with the lack of information she received about her condition and was angry that her oncologist had scheduled a meeting with a Quest social worker before discussing it with her. It was not until Katherine's son arranged an appointment with an oncologist, who he had grown up with, at another facility, that she learned more about hospice and decided that these services would be beneficial. Katherine said: "It was good to these things from another doctor, but I was mostly glad he was somebody who actually cared about me. He was [Chris]'s friend so he wasn't gonna be pushing me in a bad direction." Noteworthy here is that Katherine described her willingness to trust this physician because of his personal relationship with her son more so than his expertise as an oncologist. Like Rose, Katherine also noted how discussing hospice with a person she had a relationship with allowed her to inquire about specific services in a comfortable environment. "I felt more comfortable with him, nothing to do

with being a doctor. He understood where I'm coming from. We share the same values, so I could be honest with him. He knew the things I needed to hear," she told me.

In addition to the examples described above, where patients and caregivers went outside the formal health system to solicit advice and obtain information from family and friends, other participants described scenarios where unsolicited recommendations influenced their decision to access hospice services. These recommendations took on a variety of forms. Recall that Richard (caregiver), in the previous section, noted how his mother decided to enter hospice care before he arrived at the hospital. During our conversation, Richard explained that he did not challenge or question her decision because a close friend had spoken so highly of Quest after the death of his own mother. He said:

The biggest thing for me was having my friend, [Sam], who was a big supporter of [Quest] after his mother passed. He had told me so much...I even remember that they talked about hospice at his momma's funeral, saying how good it was. So that, along with my mother's wishes, made the decision easy.

Jason, the caregiver for his friend Olivia, described how his stepbrother's wife had first introduced him to hospice: "I remember how much [Stacy] talked about hospice when they took care of her mother" (field notes, April 10, 2012). When Olivia's condition worsened to the point where her doctor suggested she would benefit very little from further treatment, Jason said he was the one who suggested they look into hospice. "The doctor seemed surprised I brought it up, but I had made up my mind," he explained (field notes April 10, 2012).

In telling stories that described placing trust in close friends and family when making decisions about hospice, participants indicated that the alternative hospice definitions described in the first section of this chapter also originated in conversations with others. For example, Kevin (patient) said he first got the idea that entering hospice might help him build his strength for further treatment from a friend whose brother had received care from Quest for two months before returning to chemotherapy. “He was saying how he bounded back so quick, gained weight, had more energy, so I thought I could do that too if I could qualify,” he explained. Later in the interview, Kevin emphasized that his friend was able to describe hospice in a way Kevin could connect with because of their shared history. He said:

We came up together, so he knows what I’m about. The things that matter to me. He knows that, as a Black person, the idea you gonna let the doctor just decide that you are done...He knew I wouldn’t be alright with that, so he gave me some perspective on what I could do.

It was the same friend that told Kevin he should keep his desire to return to treatment a secret when discussing hospice with his physician or Quest representatives (i.e., the practice of “going along” described in the first section of this chapter). Geraldine (caregiver) shared this experience: Her neighbor, who had previous experience with Quest, told her that she would be best served by “acting like you are accepting that your Momma is fitting to pass on.” Interestingly, participants, like Leroy (hospice patient), described how they were sharing these alternative hospice definitions and strategies with their own family and friends. He told me:

I have talked to some people that I knew and I would tell them why you don't get go to a hospice, because they have a nurse that comes to help you. People would say, 'Oh no man, I am not letting myself die. Hospices help take care of people when they are dying.' I would tell them I am not dying. You see I am still living and you could be the same. Maybe the hospice could help you live longer too...You might have to deal with people saying it might only be a few months but s---, you just nod and move on. You just do what you gotta do.

In the context of hospice decision-making, patients and caregivers' stories highlighted the role of individual, familial, and community networks in sharing information and making meaning about specific aspects of hospice care. Through these informal networks, participants were able to gain specific information from trusted individuals, which allowed them to make decisions about hospice.

Discussion

As an integrated part of the mainstream health system, hospice is intimately tied to the political, economic, and legal institutions in which it is embedded (see Giddens, 1984; Scott, 2008). In conjunction with these social institutions, hospice, as a form of medical care, imposes "restrictions by defining legal, moral, and cultural boundaries, setting off legitimate from illegitimate activities" (Scott, 2008, p. 50). Within the biomedical framework of the United States health system, designations of "legitimate" or "acceptable" behaviors are tied to the core values, beliefs, and policies of the larger system (Dutta, 2008; Giddens, 1984; Scott, 2008). Through its connection to the Medicare Hospice Benefit, for example, hospice reimbursement is restricted to those who physicians "certify" as having less than six months to live and agree to forgo curative treatment (Scott, 2008). From the perspective of the patients and caregivers who took part

in this study, restricting access to those who meet these criteria meant that hospice endorsed a particular “canonical” decision-making narrative (Bochner, 2002; Bochner et al., 1997). As Bochner et al. (1997) describe, canonical narratives are those that represent “the ‘right story’ which, on the whole, is taken for granted as the way things are supposed to work” (p. 314; see also Bruner, 1990). In relation to hospice decisions, the canonical narrative suggests that patients and their loved ones accept a terminal diagnosis and begin preparing for the end of the patient’s life by focusing on palliative care.

Although institutional structures, such as the U.S. health system, develop policies and procedures that regulate human behavior, limit access to resources, and create systems of authority, it is important to remember that these institutional “rules, norms, and meanings arise in interaction, and they are preserved and modified by human behavior” (Scott, 2008, p. 49). Giddens’s (1984) *duality of structure* suggests that, as social agents who know “a great deal about the conditions and the consequences of what they do in their day-to-day lives” (p. 281), humans have the ability to act in ways that align with and/or challenge institutional structures (see Dillon & Basu, 2013). Consistent with this understanding, the CCA highlights the agentic capacity of marginalized members of society to work within the cultural frameworks and social structures that envelope their lives in order to meet their health needs (Dutta, 2008). This theorizing is evident in the stories presented in this chapter, particularly in the ways patients and caregivers created alternative definitions of hospice. While the majority of participants were able to accept the institutionally sanctioned definition of hospice, others found this understanding to be inconsistent with their cultural/familial beliefs and values. These patients and caregivers actively (re)constructed new understandings of hospice while

engaging in communicative actions, such as pretending to accept that the end of life was near or that they were ready to discontinue curative treatment, that would make them “legitimate” recipients of hospice services from the perspective of gatekeepers, such as physicians and hospice providers.

These actions constituted an act of resistance on the part of patients and caregivers (Dutta, 2008, 2012; Farmer, 2003), as they were able to subvert the formal health system in order to gain access to needed services that, from their perspective, would have otherwise been unavailable. As Dutta (2008) argues, “In the medical context, resistance to the dominant biomedical discourse offers a space for interrogating its power and, ultimately, for shifting this enactment of power” (p. 223). By understanding hospice in their own ways while “playing along” with the definition described by physicians and hospice providers, participants made use of the power imbued on these individuals by the health system in ways that allowed them and their loved ones to benefit from hospice care on their own terms. Furthermore, by sharing these alternative definitions with others, as Leroy and others described, participants resisted the canonical hospice narrative and provided the means for others to access needed resources through these resistive actions (Dutta, 2012).

Even as patients and caregivers positioned their alternative understandings of hospice, apparently as resistive to their perception of the institutional definition, questions remain regarding the necessity of these alternative meanings. Participants in this study understood hospice as a system of care for patients near the end of life, which, from their perspective, would not allow for individuals who planned to continue curative treatment to receive hospice services. The NHPCO (2012), however, estimates that nearly

280,000 hospice patients are discharged alive each year for a variety of reasons, including pursuing curative treatment. Thus, it seems that viewing hospice care as a way to prepare for future treatment is a potentially legitimate understanding. Additionally, participants suggested that understanding hospice as a way to extend life, as opposed to preparing for death, was counter to the institutional definition. However, given that the hospice movement emerged as a way to ensure that patients were not forced to endure curative treatments that would offer little benefit and produce undesirable side effects, it is disconcerting that viewing hospice as a way to extend life and avoid debilitating medical care was perceived as outside the realm of acceptable understandings or that patients felt the need to hide this narrative from their health care providers.

The results presented in this chapter suggest that the way individuals understand and communicate about hospice and the Medicare Hospice Benefit, both inside and outside the health system, may produce a perception that hospice access is more restrictive than it is/could be. In particular, the notion that an unwillingness to accept that a physician can predict when a person will die and/or a desire to pursue curative treatment in the future makes a person an “illegitimate” hospice patient raises serious political and ethical questions. Although participants in this study were able to work within the health system to access hospice care while understanding it in alternative ways, others may find it difficult to see beyond the institutional definition and/or be unwilling to “go along” with physicians and hospice providers in the way participants in this study described. Given that these definitions center on issues of prognosis and discontinuing curative treatment, the results of this chapter, once again, support the need to revisit hospice eligibility policies. All of the participants felt they or their loved ones

would benefit from hospice services. Yet, those who perceived that their cultural/familial values did not align with their institutional understanding of hospice, as communicated by health care providers, felt they had to act in deceptive ways in order to access these services. This finding again begs the question: is it necessary and/or ethical to force patients and their loved ones to make the “terrible choice” of continuing with curative treatment or accessing hospice services (Casarett et al., 2009; Fishman et al., 2009)? As Fishman et al. (2009) point out, “other Medicare-supported services do not require that patients forgo one treatment to get another” (p. 695). As evidenced here, the continuation of the Medicare Hospice Benefit’s either-or policy may force individuals who would benefit from hospice to forgo this care or find ways, as participants in this study described, to “play along” with physicians and hospice providers.

Also evident in participants’ decision-making stories was the link between culture, identity, and health (Arrington, 2000; Basu & Dutta, 2011; Dutta, 2008). Identity refers to ways in which individuals understand themselves in relation to others and is tied to one’s cultural experiences and meanings (Basu & Dutta, 2011; Dutta, 2008). As Dutta (2008) writes:

Culture provides the contextual space within which individuals develop a sense of self, come to value certain aspects of the self, and come to enact this self-concept through their day-to-day actions. (p. 90)

An essential aspect of the meaning and relationships that individuals create with others, identity also “acts as the axis on which cultural participants frame responses to health messages, adopt healthful behaviors, and negotiate treatment patterns” (Basu & Dutta, 2011, p. 108). Making sense of identity, health, and culture is often tied to family stories

that socialize family members into the larger cultural system (e.g., Dutta, 2008; Jorgensen & Bochner, 2004). For example, in linking her hospice decision to the cultural value of family caregiving, Jasmine told me, “My momma and aunts and uncles, we always talk about caring for our people when they need it. That’s part of who we are as Black people.”

The findings discussed in this chapter support previous research in highlighting family caregiving as an important feature of many African Americans’ cultural identity, particularly in making sense of serious illness (Bullock et al., 2005; Campbell et al., 2010; Smith, 2004; Taxis, 2006). The majority of these studies have pointed to this value as a potential barrier to hospice utilization. This study, however, suggests that the importance of family caregiving may also serve as an impetus for entering hospice care. For example, many participants described hospice as a mechanism for them to exercise greater input and control over the formal care their loved ones received. Others saw hospice as allowing them to play a central role in their loved one’s care while providing services they would not otherwise have access to. Finally, for participants like Leroy, hospice offered a chance to maintain important features of their identity (i.e., parenting) even while dealing with a serious illness.

Central to all of these examples is an understanding that culture, as a vital aspect of identity, is both static and dynamic. Culture is static in the sense that it offers an overarching web of meaning that influences values, beliefs, and practices (Airhihenbuwa, 2007; Basu & Dutta, 2011; Dutta, 2008; Geertz, 1973). At the same time, these webs of meanings are also contested and open to renegotiation as contexts, relationships, and circumstances change over time (Airhihenbuwa, 2007; Basu & Dutta, 2011; Dutta, 2008;

Geertz, 1973). In the context of illness and death, the meaning patients and caregivers assign to cultural values and practices, like family caregiving, can shift as they experience physical deterioration and the need to make choices about care (Dutta, 2008; Ellis, 2000). Thus, central to making decisions about hospice, or any other health care choice, is communication (i.e., the active, relational process of making and sharing meanings). As noted in the examples included in this chapter, patients and caregivers were able to assign a variety of meanings to the shared cultural value of family caregiving that addressed their specific circumstances and met their contextual needs.

The centrality of communication in making decisions about hospice was particularly clear in Milton's story. He noted how his families' identification with Christian spirituality, another cultural feature that has been labeled as barrier to hospice use (e.g., Winston et al., 2005; Yanchu et al., 2010), influenced their decision to use Quest's services. Milton stated that the family had been praying that medical treatments would heal Karen. After meeting as a family, however, the family "stepped back and said we have to trust that God is putting us in this position for a reason." Once again, this meaning was constructed or constituted in interaction among the family members. As these examples demonstrate, it seems making decisions about hospice is less about the "factors" patients and caregivers consider and more about the meaning that they assign to these factors through relational communication processes. This raises questions about the viability of isolating decision-making factors and/or cultural barriers that can be incorporated into targeted health messages and educational materials designed to promote hospice among African Americans, as it may be difficult to account for the divergent

meanings that individuals assign to cultural values/practices amidst differing contexts and (often) rapidly changing circumstances.

Participants' stories also highlighted the role of everyday, informal communication as a central feature of their decisions about hospice. As Cline (2011) argues, health communication, as a field of inquiry, theory, and praxis, "has focused more on formal than informal contexts and on planned [rather] than incidental or everyday messages" (p. 377). This focus ignores the prominent role that everyday, informal interpersonal communication plays in making sense of health information and making health care choices by focusing on formal contexts (e.g., doctor-patient communication) and planned health messages (e.g., responses to health messages disseminated by public health experts; Cline, 2011). The relative absence of research on relational and informal health communication is also reflective of the expert bias of the mainstream health system (Dutta, 2008). As Pal (2008) writes, it is typical for "dominant academic knowledge [to be] invested in understanding what the dominant system wants to know" (p. 3). Consistent with the dominant approaches to health communication and disparities research (Dutta, 2008; Thomas et al., 2011), scholars often point to the use of formal communication channels and planned messages as the mechanism to address hospice disparities among African Americans. These suggestions assume a level of centrality and trustworthiness of formal health communication in hospice decision-making that is not supported by the current findings. In contrast to highlighting formal communication (i.e., conversations with health care providers, printed materials, etc.), participants' stories centralized informal communication with family members and friends (e.g., soliciting advice and obtaining information) in making decision about hospice. In these stories,

health care providers, as gatekeepers of hospice services, played a necessary yet incidental role in patient and caregiver's decisions. In many cases, participants felt the need to go outside the health system in order to obtain specific information or garner a "trusted" recommendation about hospice. This suggests that relying on formal communication channels to disseminate hospice information to African American patients and their loved ones is likely to have limited impact.

Conclusion

Taken together, the findings regarding hospice utilization decisions presented in this chapter suggest the need to look beyond persuasive messages and educational materials as the primary method of addressing disparities in hospice utilization. In addition to reforming health policies that restrict access and promote a narrow understanding of who can "legitimately" make use of hospice services, it is important to look beyond formal communication channels and attempt to tap into relational forms of advocating hospice care (see Chapter 6 for more on this topic). This chapter also supports Cline's (2011) argument for greater consideration of everyday, interpersonal communication among health scholars; participants' narratives indicate that there is much to find in this "neglected box" of health communication research (p. 377). In the chapter that follows, I continue to focus on this "neglected box" by considering how participants' narrate their experiences with illness and hospice care.

Chapter 5:
The Complexity of Hope:
Patients and Caregivers' Experiences with Terminal Illness and End-of-Life Care

As evidenced in Chapter 4, the current focus on addressing disparities in hospice utilization by creating message-based health campaigns that incorporate decision-making factors and cultural barriers fails to account for the dynamic nature of culture or the relational, communicative processes that shape hospice decisions and experiences at the end of life (Cline, 2011; Dutta, 2008; Ellis, 2000). Based on the notion that narrative is “an indispensable theoretical and methodological guide for understanding and then addressing health-related” issues (Bute & Jensen, 2011, p. 213), this chapter focuses on the study’s third research question: *RQ3: How do African American patients and caregivers describe their experiences with hospice care?* Drawing from patient and caregiver stories, I examine how participants make sense of their hospice experiences as way to gain insight into the intricacies of communication within personal relationships in the context of terminal illness (Ellis, 2000). More specifically, I use a modified version of the narrative typology used by Bute and Jensen (2011) in their study of narrative sensemaking about sex education among low-income women. Their study grouped

participants' narratives⁹ into three categories: narratives of regret, narratives of satisfaction, and narratives of uncertainty. I maintain the first two categories in this chapter but modified the third to include the "narratives of ambivalence," a category that was more reflective of participants' accounts (see Table 5.1).

Table 5.1

Participants: Organized by Narrative Categories (N = 26)

Satisfaction	Regret	Ambivalence
Charles	Carla	Katherine
Leroy	Bridget	Mandy
Jane	Pearl	Belle
Kevin	Jason	Roger
Lisa		Keisha
Betty		Milton
Jeannie		Robert
Martin		
Richard		
Jack		
Geraldine		
Ruth		
Jasmine		
Carl		
Julia		

Narratives of Satisfaction

Narratives of satisfaction involved discussions about how hospice care met salient needs for both patients and caregivers in a way that aligned with participants' contextual needs and cultural/familial values. All 15 participants (8 patients, 7 caregivers) who communicated narratives of satisfaction described how hospice provided a level of care that would have been impossible in a hospital or if the family was providing care on their

⁹ Because they did not participate in formal interviews, Carolyn, Joan, Stephen, and Rose were not included in the analysis for this chapter. Thus, the sample for this chapter was reduced to 26 participants (see Table 5.1).

own. Jasmine stated: “I do not know what I would have done without [Quest]. I couldn’t take care of [Martin] without them.” Geraldine wished everybody was able to experience hospice care. “The people from hospice are angels. I would want anybody who is caring for somebody to have hospice there to help. They help you so much,” she said. These examples demonstrate participant discourse related to hospice care—where hospice aids caregivers in providing high quality care to sick and dying loved ones. This construction positioned hospice as a partner in offering the “best care possible to [their] loved ones” (Belle).

Similar to Jasmine’s assertion that she could not have provided the same level of care to her mother without hospice, Jack said that Quest allowed him to meet his responsibilities as a caregiver for his wife Lisa. He told me:

It’s like I was saying earlier, caregiving is an important part of how I was raised. I had not heard anything about hospice before but once they came in to talk to me about how it would provide things I couldn’t do, I knew it was the right thing to do for her.

Like Jack, other participants focused on the resources that Quest provided to help them care for their loved ones. In addition to administering pain medication that was “a million times better than what we were giving her” (Geraldine), the caregivers pointed to Quest’s medical equipment (i.e., wheelchairs, hospital beds, shower chairs) as a mechanism for keeping their loved ones at home. Ruth, for example, explained how Quest’s services allowed her husband to be cared for at home:

I knew that the hospital could only do so much because although they were helping her with their pain management...but hospice could do a little more to

keep her comfortable. He wanted to be here with us. So that was my ultimate goal I wanted to get him back home, so I could care for him, and [Quest] made that happen.

Patients also highlighted the ability to receive care at home a great benefit. “I was so tired of being in that hospital. I wanted to be home so bad,” Martin told me.

Others pointed to the training that Quest’s employees offered to help family members provide quality care. “So there were nurses coming in with the meds and teaching me...I learned how to do everything for her and they taught me how to do it...I was about to break my back lifting her,” Jack said. As caregivers and patients described the specific benefits of hospice care for their loved ones, there was a consensus among them that hospice was the “right choice” (Carl, field notes, April 23, 2012) and the “best option” (Jasmine) for them and their family.

In addition to describing the specific benefits of hospice, all 15 participants who told narratives of satisfaction also noted how their experiences with hospice fit with their cultural/familial values and practices. In particular, these stories included descriptions of caring for sick and dying family members ($n = 14$) and Christian spirituality ($n = 11$) as values participants associated with African American culture. For those like Jasmine, hospice served as a manifestation of these values. She explained:

Well, it’s like my momma always told us, because when it comes to Black people and white people, White people raised like, when they get old they don’t have time for them, they get rid of them. Black people don’t do that. They have time for their family, they take them in and take care of them [inaudible]. White people don’t do that. White people put them in an old folks home or whatever and keep

going about their lives. Black people don't care, they stop and take care of theirs, always have, always been my family like that.

Lisa provided an example of associating hospice with spirituality. "I have always thought that God sent these people to us for a reason. They bring His light into this place whenever they come in," she explained. Others also pointed to the availability of participating in Bible studies and having in-home chaplain visits as contributing to their satisfaction.

A third prominent feature of narratives of satisfaction was the feeling that participants' present circumstances were consistent with what they had hoped for upon entering hospice care. Thirteen of the participants who shared a narrative of satisfaction shared this feeling. Geraldine and her mother Betty, for example, viewed hospice as a way for her to regain her strength so that she could pursue further curative treatment. At the time of our interview, Geraldine felt vindicated, as Betty's condition had improved. She explained:

And she's doing great. I mean she have gained some weight. She hasn't let it worry her so I am not going to let it worry me. It's in God's hands and I mean she's doing awesome. She's doing really, really good. Her spirits is uplifted you know.

Similarly, others described satisfaction with their hospice experience because it fit with their expectations as patients and caregivers. Jeannie, a hospice patient with lung disease, noted how her hospice experience was "exactly how she had hoped." She said:

I knew I was very sick and that God was fitting to take me soon...I wanted to be at home and not be in so much pain. And [Quest] they doing what they said they

could... So here I am with my kids around and feeling good about what's happening.

Ruth recounted how a close friend who had recommended hospice assured her that David's (her husband) death would be peaceful and that she would have the chance to stay with him the whole time. As she narrated, this was consistent with her experience:

Ruth: On the 21st of August and we went to the Ruskin's hospice house, they did everything. They did everything, I mean, I didn't have to really do anything but sit there. The majority of the time I was sitting talking to him, reading scriptures, and singing. We would sit there and I sit there and talk to him just like, it just felt like home, basically. As I had told them this somewhere he wanted to go, if he could not come home this is where he wanted to go to the hospice house. This is where he went to the one is Ruskin. It was nice; you had your own little suite area and your own room area. And of course pull out couch there that I could sleep there. Matter of fact the whole seven days I didn't even come home, I just stayed.

Me: You just stayed there.

Ruth: And was so peaceful and wonderful, just like my friend said it would be... So we had not and we never had, or what you would consider a honeymoon. But I told him I said, you know this feels like a honeymoon but it is not really our honeymoon. I knew that he could really hear me.

Me: So it was like you had expected?

Me: Oh yeah. Nice and quiet time, staying together, exactly how I thought it would turn out.

Beyond the 13 participants who communicated a narrative of satisfaction and felt their experiences met their expectations, Jack and Lisa explained that their experience with Quest had been better than they expected. Seven months before I interviewed both Jack and Lisa, her doctor predicted that she “had less than three months to survive. So it was some pretty serious stuff” (Jack). Jack arranged for Lisa to be brought home in preparation for the end of her life. By the time of our interview, however, Lisa told me:

I’m doing so much better. I wouldn’t say like back to myself but I don’t feel like I am dying. I give y’all at Quest all of the credit. I wouldn’t be doing so well if it wasn’t for all of the help we have gotten.

Lisa and Jack viewed their hospice experience positively because they had a more positive outcome than they had expected.

Narratives of Regret

Narratives of regret were characterized by participants’ disappointment with their hospice experience. Four caregivers communicated narratives of regret. Three of the individuals who shared a narrative of regret suggested that the primary reason they viewed their experience negatively was that their loved one’s referral to hospice came too late (see Teno, Casarett, Spence, & Connor, 2012). Jason explained that his friend, Olivia, was referred too late because her physician did not discuss the hospice option with them until Jason suggested it. Jason was concerned about Olivia’s worsening condition, but it was a close friend who first explained what hospice was to Jason. After discussing it with her physician, the doctor agreed to refer her and Jason arranged to

relocate her from the hospital to one of Quest's inpatient hospice facilities. Olivia died three days later. Pearl also felt her husband's hospice referral came too late. George (Pearl's husband) was able to relocate from the hospital to their home and received hospice services for ten days. According to Pearl, however, he was minimally conscious for the majority of this period. "It's hard for me to think about my experience as anything but negatively because [George] didn't even know what was happening," she told me.

Bridget also shared the perception that her loved one's hospice referral came too late for her benefit from Quest's services because the physician had done a poor job of explaining their options. After being diagnosed with pancreatic cancer, Linda (Bridget's mother) underwent a surgical procedure to remove two cancerous tumors from her abdomen. After spending a few days recovering in the hospital, Bridget was able to bring her mother home. Bridget's goal at this point was to help her mother recover to the point that she could begin radiation therapy:

Me: So after the surgery no one was even talking about hospice and you probably weren't because at that time it seem like everything was going to be ok.

Bridget: And literally, I was taking care of her myself. I was her sole caregiver. She was in skill nursing facility for some time for a few months because she needed to learn how to walk again but once she was well enough to where I could at least get her from the chair to bed to another chair. I brought her home. My husband and myself took care of her and so I would work and he would work

and we would work different shifts. He would be here when I'm not.

At a follow-up appointment, a few months later, Linda's doctor discovered two new tumors that were each "about the size of a golf ball" (Bridget). The physician suggested that the family consider hospice at this time, but, according to Bridget, "he made it seem that if I called in hospice that was it." Bridget explained that she and her husband did not realize that if Linda's condition improved she could return to curative treatment and "were not ready to disregard that possibility." They continued caring for her until it became apparent that she "was not going to get back to the radiation" and called Quest. Linda survived for seven days while receiving home-based care from Quest. "If we had just started sooner, I wouldn't feel so bad about our experience, but when I look back now, it just feel awful. Like, why didn't we go with hospice a few months earlier," Bridget said.

Carla also shared a narrative of regret regarding her hospice experience. Carla was the primary caregiver for her mother, Patricia, a hospice patient with ovarian cancer. When Carla decided to have her mother enter hospice care, she did so with the hope that her mother would soon be well enough to return to active treatment. She explained:

Yeah, hospice, the lady from hospice, I talked to them. She was saying stuff like it could be a couple of weeks, a couple of months, a couple of years, nobody knows, you know that sort of thing. So I was not thinking weeks, that part, I guess I didn't focus on, I didn't hear, I am not sure what happened with that. I was just thinking that, you know, she was gonna spend some time recovering and then she'd be back with the doctor. That was my hope. It was my only focus.

Patricia's condition began to worsen about three weeks after she started in-home hospice care. When Carla woke up one morning, her mother was unresponsive and did not want to get out of bed.

I had kind of a hard time with that because I wasn't realizing that she was getting, that she was as sick as she was, I didn't realize that I guess because she had just been up the day before. So I wasn't seeing that and I was saying, Ma, you not gonna just lay here, we're gonna call Ms. Hanna, I said, you're not just gonna lay here and not do anything, you gonna have to move around. And she didn't want to eat or anything, but I was giving her like soup and stuff, and I was standing there feeding it to her and the lady said well you know she might not really need that and I guess she was trying to explain to me that she was really leaving.

Patricia did not get out of bed that day. After a few more days where "she was kind of in and out of it" (Carla), Patricia died. As Carla reflected on her experience, she suggested that if she had realized her mother was going to die after a few weeks, she would have chosen to continue curative care:

I heard months and years and I did not hear weeks and she passed in three weeks, so I was not hearing that she might go down so quick. I guess, like I said, I did experience, even for the situation, what it was, no it was not the greatest experience. I mean if I had known she was not going to get well enough to go back to the doctor, I'm not sure what we was doing. Nothing against what hospice is, but I would've done it different if I had another chance.

In contrast to the narratives of satisfaction, in the previous section, that centered on participants' hospice experiences proceeding as (or better than) they expected, Carla viewed her experience negatively because her mother was not able to return to curative treatment.

Narratives of Ambivalence

Narratives of ambivalence were marked by expressions of opposing or conflicted perceptions of one's hospice experience. Seven participants (two patients, five caregivers) shared narratives of ambivalence. All seven stories contained similar elements to the narratives of satisfaction described above. In particular, participants' pointed to the benefits of hospice care while noting how the decisions to use Quest's services aligned with their cultural/familial values. "I am like anybody else, when I make a decision like this, I am thinking of who I am, how I was raised," Keisha said. When Karen (Keisha's aunt) developed cancer and did not respond to several months of curative treatment, Keisha and her husband Milton were forced to make a decision about how to care for her. In describing her experience with hospice, Keisha reflected on the cultural importance of caring for sick and dying loved ones. She stated:

If you come to understand wanting to take care of your family and wanting to be the one who controls everything then you would know how African American homes are. It's an important value of ours, you know, taking care of our own. So I and really Milton saw hospice as the best way to do that for my auntie. [Quest] would give some help but we ultimately be the ones who took care of her. She deserved that.

Also similar to what is apparent in the narratives of satisfaction, participants pointed to spirituality as an important aspect of their experience. "With the religious connection,

that was perfect for my mother. She was very into Jesus Christ. I knew in that scenario she would be cared for in the proper way,” Roger told me. Patients and caregivers also spoke of the tangible benefits of hospice and their satisfaction with individual providers.

Mandy, a patient with cancer, shared this:

Yes, I’ve been real happy. Because I used to have to have somebody come in and give me a bath every day. Now they cut it down to two days a week. I could bathe so she usually helped me in and out of the tub, make sure I didn’t fall or anything like that. I have a nurse come here every other week and check my pressure and all of that. Everyone’s been real nice...Like I say there’s a nurse and another lady that comes back and gives me a bath. Everybody’s been good. They call me on Thursdays and see if I need medicine.

Similarly, Richard explained: “There was nothing that could have been better from a care standpoint. Everything hospice said they would do is exactly what happened.” Thus, overall, narratives of ambivalence shared many elements of the narratives of satisfaction, including access to quality care, medical supplies, and spiritual services.

In addition to describing their satisfaction with hospice services, however, participants who communicated narratives of ambivalence also pointed to aspects of their experience that left them feeling “down” (Katherine), “hurt” (Roger), or “remorseful” (Belle). Katherine and Mandy, the two patients who shared narratives of ambivalence, noted that although they were happy to have access to high quality care, they wished they were well enough to return to curative treatment. Katherine captured this perspective in saying: “I feel so blessed to have nurses like [Chelsea] come and help me. I feel so good about that. I knew I was coming up on the end when I got here. It’s hard. I would wish I

could just get better, not be so sick.” She went on to explain, “I know it’s probably not happening but I would love it if there was something more the doctor could do.” Similar to Carla in the previous section, Mandy entered hospice hoping she would be able to return to curative treatment. “I was thinking I might start doing better, but I’m feeling pretty much the same as I was. I’m not worse, but I wanted to be better.”

The negative feelings that marked the five caregivers’ narratives of ambivalence centered primarily on conflicts with close family and friends. These conflicts focused primarily on the meaning and appropriateness of hospice as a way to care for their loved ones. They described encountering divergent meanings of hospice care that positioned utilizing these services as an abdication of cultural/familial responsibilities by pushing caregiving on to non-family members and, in some cases, as a way to hasten patients’ deaths. Richard, for example, recalled how one of his neighbors said hospice is “like killing your parent.” Milton described how a similar interaction with one of his friends left him feeling stigmatized for using hospice services:

Black Americans don’t understand. And then they stigmatize you for being the one who allowed Hospice to come in. My friend’s like, ‘Oh, I can’t believe you would do that to your auntie. How would you feel if someone just left you to die?’ And I’m sitting here like, ‘I’m doing the best thing I can do for her.’ It’s tough, you know, it’s like hard enough to deal with all the taking care of her and then you have people looking down on or questioning you. They just haven’t been there.

In addition to feeling stigmatized, divergent understandings of hospice also led to the dissolution of close relationships and/or affected the care that patients’ received.

Roger told me: “My brother [Kyle] exploded when the doctor brought up hospice and it just got worse when I said I supported it a few days later.” He went to explain that his brother refused to interact with his other siblings or speak with any Quest employee after the rest of the family decided to enter their mother into hospice care. Roger added:

He would only come visit Mom when nobody else was there...and he kept trying to convince her we were doing something wrong. He kept telling her, ‘Don’t let them make you give up.’ When she passed, we had to beg him to even come out to the funeral.

Four months had passed since their mother’s death when I interviewed Roger, and at that time, his brother remained estranged from the rest of the family.

Belle, the caregiver for Curtis (her father), also shared a story about an extended conflict with her father’s sister that centered on divergent understandings of hospice care. Upon hearing that her father, who was suffering from lung cancer, was too weak to continue curative treatment, Belle made arrangements for move him to an inpatient hospice facility. After meeting with a Quest representative, Belle phoned her aunt, the only surviving member of her father’s immediate family, to let her know what was happening. As Belle recounted, “She wanted him to be at home, me be there by myself taking care of him. She kept saying, ‘This is what we do. Nobody else should be taking care of him.’” Feeling pressure from her aunt, Belle agreed to try to care for her father at home. After just one day, Belle’s father began experiencing severe pain and was having difficulty breathing. At this point, she decided that it was time to call Quest:

Like I said I promised them [her family] I would do everything I could to help him. It just got me kind of frazzled when the shallow breathing set in so quickly.

He kept saying, 'Help, help!' And I was literally, his mouth was so filling with mucus, and I was putting on gloves going in there and propping him up, trying to keep his mouth clean, and keep his air way open. He kept saying, 'Please.' I said, 'Okay, Dad. I promise you, promise you, as soon as day breaks I'm going to get you some help.' That's when I called and they [Quest] came out to assess him and they called for an ambulance. We took him straight from the house to the hospice house.

Belle's father died three days later. After his death, Belle's aunt continued to call and tell her that she had made the wrong decision, that she had given up on him and not "done what a good daughter should do." Belle's aunt also began calling "the older cousins to tell [me] that I am wrong." The conflict between Belle and her aunt even extended to decisions regarding his funeral and burial. As Belle explained her hospice experience in hindsight, she told me she still thought that she made the best decision for her father's care. She said:

I look at just like what I said. I still, my rules is that my father asked me for help and I couldn't stand the suffering. He said, 'Get me some help.' Those were his last words. I said I promise I will do it. But that doesn't mean it didn't hurt to make that decision. I remember sitting at his funeral thinking that maybe I could have lasted a few more days on my own. I could have kept him at home. I still think that sometimes. I feel remorse for what I did.

Even as Belle expressed comfort in her decision, she also admitted to feeling a sense of guilt or remorse regarding her experience. Similarly, Milton juxtaposed his

assertion that he knew “he did the right for [Aunt Karen]” with a sense of regret. He noted:

I think it is something Keisha and I will have to live with until more people take the steps to learn about it [hospice] or try to see it a different way. I mean, you know you did the right thing for [Aunt Karen], but it’s not like you don’t care or it doesn’t hurt. You can be sitting there sometimes and be like, ‘Damn.’ I mean it’s especially when people say stuff like ‘you did your auntie wrong.’ But, at the same time, I can always look back and remember how much better those last days were because of what Quest did.

Thus, even as caregivers like Belle and Milton expressed reasons to support their choice and expressed satisfaction with hospice care, they also noted how competing conceptions of their experiences and relational conflicts left them feeling a simultaneous sense of remorse.

Discussion

This chapter examined patients and caregivers’ narratives in order to understand how they make sense of their experiences with hospice. Although each individual told a story that encompassed unique circumstances and relationships, common themes emerged across the stories that offer insight into the ways individuals assign meaning to their experiences in the context of terminal illness and end-of-life care. The majority of participants shared narratives of satisfaction in which they highlighted the benefits of hospice care and its congruence with their cultural/familial identities and traditions. Narratives of satisfaction also centered on a sense that one’s experiences with hospice met (or exceeded) his or her expectations. Other participants narrated stories of regret,

stories that focused on late hospice referrals, misunderstandings, and unmet expectations. Finally, a number of participants offered narratives of ambivalence in which they expressed conflicting perceptions of their hospice experiences. As these participants described satisfaction with the care they received, these feelings were offset by messy conflicts surrounding divergent meanings of hospice and desires for different outcomes.

The results of a recent study by Bute and Jensen (2011) highlighted the importance of retrospective sensemaking in stories about health experiences. More specifically, their analysis of low-income women's narratives about sex education suggested that "a lapse in time between lived events and their narration is important to the process of sensemaking" (Bute & Jensen, 2011, p. 228). It is also important, however, to remember that narratives are not only about looking backward. Rather, "the stories we tell [and live] are remembrances of the past situated in connection to the present moment...and toward an anticipated but uncertain future" (Bochner et al., 1997, p. 313; see also Crites, 1971, 1986). Noteworthy in the present findings is that a primary feature of narratives of satisfaction, like those shared by Geraldine, Lisa, and Ruth, was the sense that one's present circumstances confirmed (or exceeded) a previously anticipated future. This sense allowed participants to look back on their previous experiences fondly and, for those who were still receiving care at the time of the interview, provided a sense of hope for the future. As these patients and caregivers found themselves living in what Ellis (2000) describes as two simultaneous realities—one in which the patient is near the end of life and one where recovery is possible—it was clear that they tried to maintain "the most hopeful frame possible" (p. 303).

As evidenced by stories like those shared by Katherine, Mandy, and Carla, however, the reality of physical deterioration can quickly shift the meanings that patients and caregivers assign to their experiences and make it difficult to maintain hope for recovery. Carla's narrative provided a particularly interesting example. Despite acknowledging that her mother's health care providers explained that her mother could die within the next few weeks, Carla was steadfast in maintaining the more hopeful frame that entering hospice was a way for her mother to prepare for additional treatment. When her mother did not survive long enough to seek further curative care, according to Carla's story, it was the juxtaposition between her expectations and the abruptness of her mother's death that left her feeling regretful for the choices she had made. In contrast to Carla's narrative, Ruth's story suggested that her expectations upon entering her husband in hospice care were for him to be pain-free and for them to be together as he neared the end of life. In adopting this (arguably) less hopeful frame, Ruth was able to look back on her hospice experience with satisfaction and contentment.

These stories demonstrate the complexity of "hope" in the context of terminal illness and end of life care. In a persistently death avoidant society like the United States (Connor, 2009), there is often pressure for patients, caregivers, and even health care providers to adopt the hopeful frame "that there [is] still something to try" (Ellis, 2000, p. 302) even when patients are very near death. While it may serve a valuable sensemaking function, it is important to note that this frame also has consequences when terminally ill patients and their caregivers inevitably face the realities of physical decline and death. Thus, although this hopeful frame may help patients and caregivers to cope with their

present circumstances, it may also make it more difficult to cope when these circumstance change.

It is often assumed that by entering hospice care, patients and caregivers have started moving down a path of accepting that the end of life may be near. The findings of this study suggest that this may not always be the case. In a recent study of communicating about end-of-life care with head and neck cancer patients, Roscoe, Tullis, Reich, and McCaffery (2013) suggested that physicians adopt a “Google Earth” approach to discussing care options “so patients can decide how to get from diagnosis to recurrence to death in a way that supports their values and preferences” (p. 190). It seems a similar approach would be beneficial in the context of hospice care, as it may allow providers to gain a better sense of how patients and caregivers understand their current circumstances as well as their hopes for the future. As evidenced by the stories in this chapter (and the previous one), these initial meanings influence the way patients and caregivers make sense of their experiences as times passes and circumstances change.

The findings of this chapter also support previous studies in raising concerns over “late referrals” to hospice care. Of the 1.6 million patients who access hospice care each year, over 35.7% die in seven days or less (NHPCO, 2012) and more than half receive care for less than 30 days (Waldrop & Rinfrette, 2009). Although they represented an extremely small sample, participants who shared narratives of regret supported previous studies in suggesting that a late referral limits the benefits of hospice care for patients and their families (Teno et al., 2012). Caregivers’ stories also followed previous studies in describing their late referrals as the result of poor or absent communication about hospice with health care providers (e.g., Teno et al., 2012; Waldrop, 2006). These findings

suggest the importance of making patients and caregivers aware of the hospice option as soon as possible, as well as the need to ensure systems are “in place to deliver high quality of care for persons who will receive hospice services for only a short period of time” (Teno et al., 2012, p. 737).

Further, the findings of this chapter address the need for greater understanding of “how family systems issues and the perspectives of multiple family members impact decision making” about end-of-life care (Mazanec, Daly, & Townsend, 2010, p. 565). Previous studies have suggested that family caregiving and preferences for aggressive curative treatment up until death, meanings rooted in African American cultural traditions, may act as barriers to hospice enrollment (e.g., Born et al., 2004; Scharlach et al., 2006; Smith, 2004; Taxis, 2006). The narratives presented in this chapter support the notion that African Americans may associate these values and traditions with their cultural identity and, thus, they may consider them when making decisions about end-of-life care. As noted in the previous chapter, however, the meanings that individual’s assign to these traditions and values are not fixed (Dutta, 2008).

Health choices, like enrolling one’s self or a family member in hospice care, are culturally situated practices and, thus, provide individuals with opportunities to enact their cultural identities in relationship with others (Dutta, 2008). As humans constitute experience through narration, they are motivated to construct stories that they can live with and within (Crites, 1971). These stories do not exist in isolation but are shaped by cultural and familial narratives that (re)construct shared meanings and routines that solidify about “how things are done” and “what things mean” (Bochner, 2002). These stories direct individuals toward particular choices and provide them with reasons for

their actions (Koenig Kellas, 2005). As study participants, particularly caregivers, were forced to make decisions about hospice care, they drew upon their cultural knowledge to account for the ways in which their actions aligned or did not align with these cultural traditions. Belle, for example, located her decision to enroll her father in hospice as a mechanism to provide the best care possible, a narrative that matched the cultural importance of caregiving. She also noted that she did not equate hospice with “giving up” on him.

Narratives are also open to contestation by others, however, as they introduce alternative conceptions or competing narratives of the situation (Bochner, 2002). As evidenced in this chapter, these competing narratives can have consequences for patients, caregivers, and relationships outside the family system. In the case of Belle’s father, for example, his quality of care was compromised due to competing understandings between Belle and her aunt. Competing conceptions of hospice also led to tension within or the dissolution of close relationships.

Even as time passed and study participants looked back on their experiences in hindsight, the ability to tell a “good story,” which linked one’s actions with cultural meanings, only went so far because they were still called to account for competing conceptions of the situation. Narrative theorist, Alasdair MacIntyre (1981) writes:

One way in which the choice between rival goods in a tragic situation differs from the modern choice between incommensurable moral premises is that both of the alternative courses of action which confront the individual have to be recognized as leading some authentic or substantial good. By choosing one I do nothing to diminish or derogate from the claim upon me of the other, and therefore, whatever

I do, I shall have left undone what I ought to have done. (p. 224, original emphasis)

In this case, competing narratives of hospice care were formulated with a particular sense of what is “right” or “good,” and thus, the caregivers who took part in this study recognized that they had “left undone what [they] ought to have done” from the perspective of others close to them. This caused them to story their experiences in particular ways but did not excuse them from the relational and/or emotional consequences of the alternative narrative. Thus, many of these participants were left with a sense of ambivalence regarding their hospice experience.

Conclusion

This chapter explored patients and caregivers’ narrative about their experience with hospice. The results suggest that the notion of “hope” can serve a variety of functions as individuals make sense of their past experiences, present circumstances, and project toward an anticipated but uncertain future. Participants also point to issues related to late hospice referrals and offer additional support for the importance of cultural identity in making sense of health experiences. The next chapter moves away from describing decisions about and experiences with hospice care in order to focus on the co-constructed solutions for addressing hospice disparities that emerged in my interactions with study participants.

Chapter 6:

Building Partnerships to Address Disparities in Hospice Utilization

As noted in the first chapter, disparities in hospice utilization leave many African Americans at risk for end-of-life experiences marked by insufficient pain management, poor communication with health care providers, and increased medical expenses. Mainstream efforts to address health disparities often produce top-down programs that are out of touch with the lived experiences of marginalized members of society (Dutta 2008). The CCA is founded on a commitment to listening to the voices of marginalized populations who are most affected by health disparities in order to co-construct health solutions that meet the articulated needs of the community (Dutta et al., 2013). Consistent with the CCA to health disparities, a main objective of this study was to collaborate with African American hospice patients and caregivers in order take an “initial step” toward developing and implementing solutions that address disparities in hospice utilization. These efforts are the focus of this chapter and attend to the study’s fourth research question: RQ4: *What strategies do African American hospice patients and caregivers suggest for addressing disparities in hospice utilization?* Four key themes emerged in response to this research question: (a) the need for structural reform, (b) promoting awareness of hospice services, (c) relational health advocacy, and (d) establishing community-organizational partnerships to address disparities in hospice utilization.

The Need for Structural Reform

As detailed in Chapter 3, the patients and caregivers who participated in this study primarily understood disparities in hospice utilization as a manifestation of inequality in the larger health system. “You won’t see more Black people in hospice if they can’t get good care in the first place,” said Robert (caregiver). In particular, patients and caregivers pointed to the need to address systemic factors that make formal medical care a financial impossibility for many African Americans; “It makes no sense that we live in a rich country but I’ve got relatives who have to worry about how to pay for a doctor visit. [laughter] I mean, that’s crazy, right?” Roger stated. In addition to those who are completely excluded from the formal health system, participants suggested that cost concerns may cause individuals to delay seeking medical care until the late stages of a terminal illness, which does not allow them to consider or benefit from hospice services. They also noted how irregular access to medical care may limit African Americans’ opportunities to build trusting relationships with health care providers. As Milton (caregiver) explained, “You really needed a trusted doctor if you are going to go along with the idea of hospice. You need to know they looking out for you and your own.”

Patients and caregivers also suggested that even when access to the formal health system is available, “Black people can’t always expect to be treated right by doctors” (Carl, caregiver, field notes, April 23, 2012) or other health care providers. As noted by Carl, participants felt that being African American put them at greater risk for mistreatment or inadequate health care. Many participants emphasized that physicians often failed to provide them with salient information about their health or inquire about

patient/caregivers’ feelings or preferences when making decisions about their/a loved one’s care. Milton explained:

Think about it. If you feel like they’re not telling you everything or just making all the decisions, not being upfront or caring what you think, and then they say, ‘We just want to make you comfortable,’ what would you think?

Further, participants noted how these negative experiences with medical care lead to concerns regarding the quality of hospice care and fears that hospice would serve as a mechanism for exploitation. “You got a lot of people who are asking, ‘Are they really going to take care of me?’ or ‘What’s the real reason they pushing me toward hospice?’” said Roger.

Finally, participants also noted that the hospice requirement to discontinue curative treatment served as a deterrent for African American patients and their families, as many associated this decision with “letting somebody die” (Geraldine, caregiver) or, worse, “killing your [loved ones]” (Belle, caregiver). Citing some African Americans’ spiritual beliefs, others suggested that entering hospice care would be equivalent to “denying the care that God put in front of you” (Milton, caregiver). Participants suggested that adjusting this policy would allow more African American patients and caregivers to use hospice services. Belle explained:

That’s gonna be the hardest thing for a lot of Black or African Americans to accept is that idea that you are kind of done. Even when I started with my dad in hospice, I wasn’t accepting that. I was thinking that he would get back to treatment at some point. I know there is some other types of [palliative] services people can get but none of those is gonna be as good as what you’d get with

hospice...So that's the thing. I mean, they've got to stop with the, 'No, you can't have hospice and still be trying to get better.' That has to go away. That's what the focus should be.

Promoting Awareness of Hospice Services

In addition to foregrounding the role of structures (e.g., limited access to care, discrimination, and hospice policy) in perpetuating disparities in hospice utilization, the patients and caregivers I spoke with expressed agreement with participants in previous studies that suggested a need to increase awareness and knowledge of hospice among African Americans in their community (Born et al., 2004; Chung et al., 2009; Jenkins et al., 2005; Smith, 2004; Taxis, 2006; Yanchu et al., 2010). "There's a lot of people who could benefit from hospice, but they don't know what is available, don't have no conception of what it even is," Charles (hospice patient) explained. Additionally, participants also pointed to common misconceptions or myths about hospice care that, in their experience, were prevalent among other African Americans. Among the key myths they identified was the belief that hospice providers would "stand by and watch somebody die" (Katherine, caregiver) or "give them something that's gonna make them die quicker" (Carla, caregiver).

Discussions with participants on promoting awareness and knowledge often focused on the message-based approaches of disseminating information through various media (i.e., commercials, websites, brochures) advocated by other scholars. There was a great deal of convergence around the idea that using media to promote hospice would produce little benefit. While participants acknowledged that some media messages, particularly television commercials, might build name recognition for Quest and provide

some awareness of the nature of hospice care, they also noted that the majority of people would be likely to tune out health messages that centered around death. This perspective is captured by Leroy (hospice patient), who stated:

It's one thing to talk about 'go get a flu shot' or 'you better get a cancer test.' You can fit those into your schedule...Nobody's sitting back wanting to think about the end [of life]. That's a personal thing, a scary thing; it's not a thing for just sending out a general message. Nobody sees a commercial and says, 'F--- me, that's how I hope I die.'

Participants also expressed agreement regarding the limited potential of printed materials, brochures, or DVDs, materials that have been used to promote particular health services at the point of decision-making in other contexts (e.g., Enguidanos et al., 2011; Kreuter et al., 2010), to help people make informed decisions about hospice. Jack explained this perspective:

It's such a deep, personal type thing that it's not enough to just get some piece of paper or watch a video...My brother's wife, she had breast cancer, and they live in Alabama, but I remember when she was diagnosed, they sent home a video, DVD or whatever, and she just sat and cried through the whole thing...You can't do that to a person when they are coming up on the end [of life], or you know, say, 'Here read this or let me set this video up for you.' You need a real person to talk to, a person you can trust, somebody who has been there.

Patients and caregivers noted that the "trustworthy person" Jack referred to in his narrative, would ideally be a physician that patients and their loved ones had built a relationship with over time. As described previously, however, participants explained that

many African Americans do not have a trusting relationship with a physician and may be skeptical of a provider's recommendation that they consider hospice care. They further noted that this mistrust and skepticism frequently extended to hospice representatives. As Roger said, "So in comes this hospice person. You've never met this person and all of a sudden they are there saying that they want to make your [loved one's] death better. Tough to swallow, especially when they part of the same system."

Relational Health Advocacy

As they pointed to the limits of message- and/or provider-based efforts to promote hospice care, participants explained that they and others often relied on information obtained outside the formal health system. In doing so, they also pointed out that they and others in the community were already working to increase awareness and understanding of hospice through their interactions with family members, neighbors, and friends. That is, it soon became clear that they and other community members were already taking an "initial step" toward promoting hospice services through informal, relational forms of health advocacy. Relational health advocacy, here, refers to ways in which individuals engage in informal health promotion efforts by endorsing particular actions or the use of particular health services through personal interactions with members of their social network. As Milton (caregiver) described, "I think it is important to spread the word about hospice, to let others know what it can do for you, so I've taken some ownership for that. I think it's important the [Quest] knows that this is happening." Charles (hospice patient) expressed a similar sentiment: "Black people, African American people we tend to look out for others like us, and I think telling people about the good of hospice is another way to do that."

For many participants, advocating for hospice use began in their own families. Belle, a hospice caregiver who was also receiving treatments for breast cancer at the time of our interview, described her efforts to ensure that her family members knew that hospice was her end-of-life care preference if her treatments were unsuccessful. She explained:

You can't always control what happens on the outside, but I do my best to make sure my kids know how wonderful is...I want them to know exactly what I want. If I'm ever in the position that my father was, my kids know they should call [Quest]...I sat them down right after his [her father's] funeral and made sure they understood...I keep reminding them too [laughter], they starting to get annoyed I say it so much.

Belle highlighted the importance of discussing hospice care with her children, and like other participants, spoke about having taken steps to formalize their care preferences by creating advance directives that included specific information about their hospice preferences. Many patients and caregivers also described reaching outside of their families to promote hospice care among friends, neighbors, and acquaintances. For many of these participants, their motivation to advocate for hospice was based on their satisfaction with hospice services and a desire to “pay it forward” because of the hospice information they had learned from others. Geraldine (caregiver) articulated this feeling:

As we got started with Quest and it was just so wonderful, I knew what I needed to do to pull that curtain up, or whatever it is, so that people realize that it's something that can help you and that person who is needing that service, your loved one that you are trying to help, that this is a better way of doing it. I saw

what a blessing it was for my neighbor there to share this with me and knew I wanted to do it for others the same. I wanted to pay that kindness forward.

Other participants described similar experiences of engaging in relational health advocacy in their personal relationships by encouraging others to inquire about hospice services, providing information about hospice, and inviting others to come and witness hospice care firsthand.

In describing their informal promotion efforts, participants noted that their friends, family members, and neighbors were responsive to their recommendations because they came from a “trusted” source. Ruth (caregiver) highlighted this point while sharing a story about encouraging a coworker to ask his mother’s doctor about hospice. She told me:

I think people can appreciate you speaking up for hospice when they know you been through it on your own. I just think it helps them, like [Daniel], my coworker, to know that I am coming from a caring place. There’s no motive for, there’s just a genuine concern.

In addition to the information coming from a trusted source, some participants noted that they were able to provide specific, contextual information regarding how hospice could directly benefit a person and/or their family. Charles (hospice patient) described how he suggested that his neighbor ask her doctor about hospice care:

I live by myself, and I know how hard it can be. I got no people here. I can’t keep track of all them here pills or change my dressings, you know, getting around or whatever. I seen [Mary], that’s that lady who live next door, wasn’t getting on too well either. I knew she had heart disease, just like me. I thought they could

probably do the same stuff they doing for me. So I go and talk to her about Quest, how they been helping me get by. I say, 'Next time you go, just ask your doctor about it.' She says she didn't know if she should, but I said 'What could it hurt?' So now when Quest come see me, they go see her too.

In this brief story, Charles explained how encouraging Mary to inquire about hospice was based on his personal experience with Quest. This is another important point for Charles, as he later explained that he believed she considered his recommendation genuine because of his personal experience with hospice care. "I think she knew I was looking out for her. She knew what they did for me and seen that I was trying to help," he said.

Participants also noted how their personal experiences with Quest allowed them to address the common misconceptions or myths about hospice care described above. "I've had to explain lots of times that hospice isn't there to put somebody down or give them medicine that makes them die. People are like, 'Wow, I didn't know they just made sure you weren't in pain and help you care for them.' It was an eye-opener for a lot of people," Ruth explained. Others noted that they were able to provide information about the role family members play in providing care, how hospice is paid for, and that hospice can be provided at home or in a facility. Keisha said:

People sometimes assume the worst about things, especially something like hospice where they have no knowledge of it. People don't want to talk about it and might not trust the doctors or whoever is trying to explain but when it's your friend or neighbor or whoever, that's sometimes the best thing. You can get the information you need, ask the questions you want to ask, whatever. You can talk about paying for it, how it's set up, what the family do, all of those things... So I

take it as an opportunity to make sure more people know what hospice has to offer. Not everybody is going to accept but there is people who will if they know.

One of the most powerful ways participants described addressing myths about hospice was by inviting others to come and witness hospice care firsthand. Mandy, a hospice patient with cancer, told me that she felt many of her friends, neighbors, and fellow members of her church were questioning her decision to use hospice services because they were unfamiliar with this form of care. “They kept saying things like, ‘Are those people really going to care for you? Make sure you’re watching them all the time’” Mandy told me. Frustrated by what she saw as a lack of understanding of the mission of hospice care, Mandy began inviting others to come and visit her when she knew a hospice nurse or nurse’s aide would be at her home. She credits these visits as changing her friends’ and neighbors’ view of hospice care because they were able to witness the care that Quest provided. Mandy noted:

It was amazing to see how they perception shifted. I think it was because they saw how loving and caring these people was to me. People like my nurse, [Jackie], come in and say, ‘Hi Ms. [Mandy], how you feeling?’ and then she’s helping with my pills and all those things. And my friends say, ‘Wow. I didn’t know this was what hospice did.’

Others, like Betty (hospice patient), described similar reactions to others seeing hospice providers visit their homes. She invited some friends to participate in an informal Bible-study meeting that she participated in with a Quest chaplain. “My friends were surprised, in a good way. They didn’t know about the spiritual part, and I think it changed their thoughts about it,” she told me.

Establishing Community-Organizational Partnerships to Address Disparities in Hospice Utilization

As the research process unfolded, my dialogic engagement with patients and caregivers provided insight into understanding the structural and social issues that contributed to disparities in hospice utilization. Given the culture-centered focus of this work, our dialogues also focused on producing specific recommendations for promoting social change in the realm of hospice and end-of-life care. In particular, the results of this project pointed to the need for developing partnerships between Quest and the local community as means of promoting structural reform and increasing awareness of hospice among African Americans.

Promoting policy reform. Participants noted that the primary way to increase hospice utilization among African Americans was to address issues of inequality in the health system. Although participants acknowledged that increasing access to health insurance and addressing discrimination in the larger health system was potentially outside of Quest's capabilities, they pointed to the need to reform hospice reimbursement policies as an issue that Quest could help them address. Robert said: "They should do it, but the people who make them kind of decisions aren't gonna listen to people like me. We would need the doctors and other higher-ups at [Quest] to take that on." As noted in the first chapter, Quest is one of the largest hospice organizations in the United States, and participants assumed this would provide them with access to policy-makers that could initiate reforms to the Medicaid hospice benefit. Milton noted: "The senators or whoever you would need to talk to aren't going to sit down and listen to me, but if you got a big organization like [Quest], I would think they would at least listen to them."

Others stated that they would volunteer to assist efforts to promote policy reforms in any way Quest needed. “I’m willing to do whatever I can. I’ll share my story, write out, record it, whatever they need. I’m committed to seeing that policy changed,” Jasmine asserted.

Building trust in the African American community. Participants suggested that inequalities in the health system led to a mistrust of health care providers and the health system. As a part of that system, participants noted that concerns about mistreatment and exploitation also extended to Quest and other hospice organizations. They also agreed that merely sending out messages or providing information in the context of making health decisions would likely produce minimal benefit. Instead, patients and caregivers suggested that Quest needed to “make a long-term effort to building trust in the African American community” (Keisha). Ruth said: “[Quest] has a real chance to set themselves apart as a health organization that cares about everyone, particularly the Black community. I think if people saw that [Quest] genuinely cared about improving end-of-life experiences, people would begin to trust them.”

Specific recommendations for building trust included partnering with existing organizations and events that were important to the community. For instance, several participants mentioned the need to work with a local organization for African American professionals and/or the local chapter of the National Association for the Advancement of Colored People (NAACP). The most prominent recommendation was to build partnerships with local churches and other faith-based organizations. Lisa (patient) explained:

You [Quest] need to get into the churches. There should be a person at every church who is the hospice person. The pastor should, I mean everybody already trusts him, for the most part, but pastors don't always have time. If they can't do it, it has to be a trusted person and it'd be better if they had been through it with their own...Maybe they could just follow a nurse around or something too. Either way, if people see that people in the church trust [Quest] than people would be more willing to look into it.

Participants also mentioned that Quest should consider being a sponsor for the local Black Heritage Festival. Jack (caregiver), for example, noted how sponsoring this event helped a local comprehensive cancer center earn goodwill. He said: "It was a big deal to people to see [Cancer Center] as one of the sponsors, out there at the event. People started looking at them different. It could be the same with [Quest]."

Integrating relational health advocacy into hospice promotion efforts. In terms of addressing limited awareness or persistent myths about hospice, participants highlighted their ongoing efforts to promote hospice through relational health advocacy in suggesting that satisfied African American patients and (particularly) caregivers were the best resource that Quest had available. Participants argued that it was important for Quest to recognize these efforts and, more importantly, to affirm individuals engaging in advocacy on the organization's behalf. "I think a lot of people like me, we tell people about [Quest] for our own reasons, but I know I would appreciate knowing that they care I'm trying to spread the word," Bridget (caregiver) said. Others suggested that if Quest wanted to create mass media messages, they should focus them on reaching out to bereaved caregivers and encourage them to tell their stories. Belle (caregiver), for

example, suggested: "They could make a commercial that shows somebody telling another person about hospice, you know, saying how great it was. At the end it could flash up something like, 'Have you shared your hospice story?' or 'Share your [Quest] story.' That would be powerful."

Participants also suggested offering support to individuals who were attempting to advocate for Quest by developing classes or workshops that focused on providing more information about hospice care and gave them strategies for sharing the information with others. According to Geraldine (caregiver):

It would be good to have some sort of class or education about how to talk to people about hospice. I'm not a doctor or nothing, so I don't always know what to tell people or have the answers for them...I don't think I need to know everything but knowing more would be help to others. So that's one thing to try.

Likewise, Milton noted that people were going to go to their family members and friends anyway. "Why not make sure that people like me are prepared to handle that situation?" he argued.

Some study participants suggested that Quest could go a step beyond encouragement and training workshops by formalizing relational health advocacy efforts in the form of peer hospice advocates or community health workers (see Rosenthal et al., 2010). They suggested training community members to accompany hospice representatives that went to meet with patients or family members for the first time.

Richard said: "I think it would be nice to have somebody there who has been through it before. People would be able to ask real questions and not feel like somebody is selling

them something. They would know they looking out for them." Keisha suggested another method of providing a similar service. She stated:

What if you [Quest] could find a group of people that would be willing to take phone calls from families that are considering hospice and be able to have them call and say, 'What's it actually like?' or 'what the experience of having [Quest] in your house like?'

Through these efforts, participants suggested that Quest could harness the benefits of relational health advocacy while expanding their reach beyond individual caregivers or patients' social networks.

Initial Impacts

As noted in Chapter 2, this project began in early 2012 and continued through December of that year. I made an initial report of the findings of this research to Quest employees and leadership in February 2013. Given the short timeframe since the project ended and the results were shared, it is impossible to evaluate the impact that this project may have on addressing disparities in hospice utilization. There have, however, been developments over the past few months that exemplify the initial impact of this project and have potential to enact significant change in the future.

Dutta et al. (2013) argue that a key marker of change in CCA projects "is the presence of marginalized community members in mainstream discursive spaces where policies are made and programs are planned, implemented, and evaluated" (p. 173). In this case, the introduction of patient and caregivers' voices has shifted Quest's understanding of disparities in hospice utilization. For instance, Quest's Chief Medical Officer remarked after the presentation of the study results: "We've always just assumed

that it was lack of understanding or willingness to look at our services. I don't think we realized the bigger picture of how it connects to discrimination in the health system or policy issues" (field notes, February 15, 2013). During the same meeting, another Quest administrator remarked: "It's amazing that we never realized it was important just to encourage people to spread the word about our services. I'm not certain we would have come up with that on our own, but it makes so much sense." These reactions are important on two levels: (a) First, they demonstrate new understandings of health issues that are based in the perspectives of those affected by the disparity; (b) second, they represent organizational leaders' recognition of marginalized populations' ability to enact agency by making sense of important health issues and offering viable solutions for addressing them. These outcomes represent initial metrics of social change because individuals whose voices had been absent are now being heard in a way that matters to the mainstream discourse on hospice care (Dutta, 2008; Dutta et al., 2013).

A second initial impact of this study was the establishment of a Quest "working group" to address minority access to hospice and palliative care. This group consists of administrators and health care providers at various levels. The group also includes two community representatives (including one individual who took part in this study). One of the initial objectives for this group is to attempt to enact the recommendations that patients and caregivers offered in this study. In particular, the group is in the early stages of exploring the feasibility of creating a peer advocate program that would draw upon face-to-face communication and the telephone program outlined by Keisha and others. The group is also working to develop informational workshops to educate bereaved caregivers about promoting hospice care in their personal relationships. Although it is

difficult to project the long-term impact of these initial developments, the community-organizational partnerships fostered by this culture-centered project offer promise for addressing hospice disparities in the future.

Discussion

This study follows previous culture-centered projects in challenging the dominant paradigm of health communication, which fails to recognize the agency of marginalized communities who are affected by health disparities (Basu & Dutta, 2009; Dutta, 2012; Dutta et al., 2013; Dutta-Bergman, 2006). As Dutta et al. (2013) argue, an important strength of the CCA is “democratizing the processes of knowledge production by engaging marginalized communities as partners” in making sense of and working to eliminate health disparities (p. 176). In sharing their stories, African American patients and caregivers demonstrated their ability to enact agency by introducing new understandings of disparities in hospice utilization as well as creative solutions for addressing them. This democratic approach allowed the exchange of health meanings and proposed solutions that would have been unlikely to emerge in traditional health intervention efforts, even those described as “participatory” (Basu & Dutta, 2009; Dutta, 2008). Many participatory health communication programs limit the involvement of community members to refining existing programs that have already been conceptualized and created by external planners (Basu & Dutta, 2009; Storey & Jacobson, 2003). As highlighted in Chapter 1, for example, Enguidanos and colleagues (2011) invited a small group of African American hospice patients and caregivers to share their stories and offer feedback on the content and design of an informational brochure. In such cases, the mechanism and nature of the intervention has already been decided by those outside of

the community and is unlikely to be radically altered by community members' feedback (Basu & Dutta, 2009). By starting with open-ended questions and listening to the stories of patients and caregivers, the culture-centered nature of this study positioned community members as the key decision makers in defining central issues and proposing corresponding solutions related to hospice disparities (Dutta et al., 2013).

A primary goal of this project was to take an initial step toward promoting increased hospice use by African American patients and their loved ones. In addition to linking disparities in hospice utilization to inequality in the structure of the health system and calling for policy reforms that address these issues (discussed in depth in Chapter 3), patients and caregivers who took part in this study appeared to follow what participants in previous research studies had stated by calling for a need to increase awareness of hospice services among African Americans. In discussing this need, however, participants of this study questioned the viability of formal, message-based approaches currently advocated by numerous scholars (Born et al., 2004; Bullock, 2011; Enguidanos et al., 2011; Johnson et al., 2009; Rhodes et al., 2006; Yancu et al., 2010). In contrast to scholarly calls for media messages and educational materials that promote informed hospice decisions, patients and caregivers, I worked with explained how they and other community members were already working to promote hospice utilization among their African American family members, friends, and neighbors. These relational forms of health advocacy are often ignored in the field of health communication. As Cline (2011) notes, scholars and practitioners tend to focus on formal health promotion efforts, particularly those that center on mass media messages, while ignoring relational health promotion efforts that emerge organically in families and communities.

This is not to suggest that health communication scholars do not recognize the importance of interpersonal communication in promoting greater awareness of health issues or meaningful behavior change. It is widely accepted that relational communication plays a central role in health promotion efforts (see e.g., Silk, Atkin, & Salmon, 2011); however, scholars' attention is most often directed toward interpersonal communication that is spurred by campaign messages and how it contributes to the success of the campaign agenda (Cline, 2011; Dutta, 2008; Papa & Singhal, 2009). For example, Papa and Singhal's (2009) examination of the entertainment-education serial *Taru*, which ran in several rural villages in the region of Bihar, India, highlighted how exposure to this media campaign led to familial/community dialogue that promoted and/or discouraged social change in relation to education, gender equality, and family planning. Consistent with the dominant paradigm of health communication, Papa and Singhal argued that exposure to campaign messages (in this case, entertainment-education programs) designed by experts outside the community acted as a stimulus that sparked relational and community dialogue related to social change.

In contrast to the dominant paradigm, the findings presented here suggest that the "spark" for promoting social change through relational communication need not always emerge from outside cultural communities. It was clear in participant narratives that they and other community members were not waiting for outside experts to address disparities in hospice utilization; they were already actively engaged in relational forms of health advocacy. As they shed light on existing forms of hospice advocacy within their community, participants further demonstrated their agentic capacities by reflexively highlighting the limitations of their relational health promotion efforts and proposing

tangible solutions for expanding their reach by collaborating with Quest. Thus, rather than positioning expert-driven resources as the "spark" for promoting awareness and utilization of hospice, participants suggested that strategies such as media messages and skills training programs provide a way to fan the flames of existing forms of hospice advocacy. Such conceptualizations represent a radical reconfiguration of the dominant health communication paradigm. In this case, participants are no longer the passive recipients of health interventions; instead, they make use of these expert resources to sustain and expand health advocacy efforts that emerged organically within the community.

One particularly interesting suggestion that emerged from this project was the integration of peer health advocates as a mechanism for promoting hospice care among African American patients and their families. Peer health advocates have long been used in health promotion efforts in international contexts (see e.g., Papa, Singhal, & Papa, 2005; Svenkerud, Singhal, & Papa, 1998) and have emerged as an important part of the United States' health care workforce in recent years. Recent estimates indicate that more than 120,000 community health workers are currently serving in a variety of health contexts across the country (Rosenthal et al., 2010). The impact of community health workers in "improving access to care and health knowledge, behaviors, and outcomes is well documented" across a variety of health conditions and contexts, including diabetes, hypertension, cancer screening, and immunizations (Rosenthal et al., 2010, p. 1339; see also Rosenthal, DeHeer, Rush, & Holderby, 2008). Evidence is also accumulating that community health workers may be particularly effective in meeting the health information needs of underserved populations (see American Public Health Association,

2009; Bodenheimer, Chen, & Bennett, 2009; IOM, 2002). In describing the effectiveness of community health workers in underserved settings, Rosenthal et al. (2010) argue that their success is based in their ability to build trusting relationships with patients and their families, offer specific information and advice, and draw upon their personal health experiences. Interestingly, participants in this study highlighted the very same features when describing the value of relational health advocacy about hospice. Thus, based on scholarly evidence and participants' experiences, it seems that the use of community health workers has great potential for promoting hospice utilization.

Taken together, the findings presented in this chapter provide additional evidence that the participatory processes and academic-community-organizational partnerships fostered by the CCA can produce new understandings of health disparities as well as propose solutions to address them (Basu & Dutta, 2009; Dutta et al., 2013). Although more time is needed to ascertain the effectiveness of the present recommendations in promoting hospice utilization among African Americans and, thus, reduce disparities in the cost and quality of end-of-life care, initial metrics of change have already emerged. In particular, the introduction of African American hospice patient/caregivers' voices to Quest's leadership is, itself, an important form of change. As Dutta et al. (2013) note, the "CCA rests on the notion that when we as academics/policy makers/program planners listen to the voices of the marginalized, there is a shift in the terrains of power" (p. 177).

However, amidst these shifts in the terrains of power and the potential positive impact of this project, there remains the potential for this participatory approach to be co-opted and refigured to suit the agenda of the dominant, structurally violent health system (Dutta, 2007, 2008; Dutta & Basu, 2013; Escobar, 1999). It could be argued that such co-

optation has already taken place, given my involvement in recording, analyzing, and documenting patients and caregivers' narratives as part of this study. Although participants took part in the process, the analysis and recommendations that appear in this manuscript and were shared with Quest's leadership are still based on my interpretations of these stories, which, as Basu (2010) notes, "are loaded with my biases and the expert's lens that I used to decode" them. Hence, even as I write and speak with a definitiveness required by academic/professional conventions, it is necessary to draw attention to the impossibility of representing the experiences of the marginalized participants who took part in this study from my position of privilege (Beverly, 2004; Dutta & Basu, 2013; Spivak, 1988). Parallel to the co-optive possibilities of this project, however, are the resistive platforms that introduce alternative rationalities of hospice disparities and create entry points for scholars and practitioners to understand/address these inequities in new ways (Basu, 2010, 2011; Dutta, 2012). Thus, this project, and others informed by the CCA, exists in a tension between co-optation and transformation.

Moving forward, there is a need to examine the outcomes of the solutions that emerge from this culture-centered project as well the processes through which they are/are not implemented in the community. The initial presentation of the findings of this study and formation of "work groups" to discuss and implement the study's recommendation have been marked by excitement and cooperation among community members and Quest employees; previous culture-centered projects, however, have noted how tensions emerge in the participatory processes over time (Basu & Dutta, 2009; Dutta et al., 2013). In some ways, such tensions have already started to emerge. For example, one Quest administrator scoffed at the suggestion that bereaved caregivers who agreed to

be a part of the work group be financially compensated for their time. The potential genesis of participatory tensions were also revealed by a Quest staff member who, following a presentation of the study's findings, asked me if I thought participants had exaggerated or were "overly sensitive" to discrimination in the medical system (field notes, February 15, 2013). As Dutta et al. (2013) argue, such conceptions emerge from those who are part of the dominant system because projects informed by the CCA "make us question, challenging our rationalities of doing good and in doing so, center the necessity for reimagining the intertwined relationship between structural inequalities and opportunities of representation" (p. 176). Thus, examining the ways in which these participatory tensions emerge and are managed among community members, academics, and policymakers is an important consideration as this project unfolds.

Conclusion

This chapter focused on the study's fourth research question by examining patients and caregivers' perspectives on strategies to address disparities in hospice utilization among African Americans. Four key themes emerged in response to this research question: (a) the need for structural reform, (b) promoting awareness of hospice services, (c) relational health advocacy, and (d) establishing community-organizational partnerships to address disparities in hospice utilization. Drawing from these themes, participants offered specific suggestions for advocating for hospice policy reform, building trust in the local African American community, and integrating relational forms of health advocacy in hospice promotion efforts. The initial impacts of these findings support the viability of the participatory processes foregrounded by the CCA in producing new understandings of health disparities and community-based solutions to

promote health equity. In the next chapter, I conclude this dissertation by describing the contributions and implications of this study.

Chapter 7: Conclusions and Implications

This dissertation study reflects theoretical and empirical contributions to understanding and working to eliminate disparities in hospice utilization among African Americans. The majority of people living in the United States assume that African American and white patients receive the same quality of healthcare and have similar health outcomes (Lillie-Blanton et al., 2000; Morin, 2001). Despite such perceptions, a substantial body of research reveals the reality that African Americans experience higher morbidity and mortality rates while receiving lower quality medical care (Kreps, 2006; IOM, 2003; Thomas et al., 2011).

In recent years, there has been an increased recognition and concern regarding disparities in end-of-life care (Bullock, 2011). In particular, extant research indicates that a disproportionate number of African Americans die in hospitals while paying more for lower quality end-of-life care (Flory et al., 2004; Taylor et al., 2007). Many have argued that a primary contributor to disparities in end-of-life care is the underutilization of hospice services by African American patients and their loved ones (Enguidanos et al., 2011; Yanchu et al., 2010). Building on this argument, scholars have worked to understand disparities in hospice use and begun developing educational materials to promote hospice services among this population (Bullock et al., 2011; Enguidanos et al.,

2011; Yanchu et al., 2010). Despite this focus, hospice usage by African American patients has remained stable over the past five years (NHPCO, 2012). Thus, there is a continued need to address inequities in end-of-life care by working to promote increased hospice usage among the African American population.

Over the past decade, a number of studies have attempted to lay the groundwork for developing health campaigns and educational materials designed to promote hospice care. Consistent with what Dutta (2007, 2008) and Dutta & Basu, (2011) describe as the *cultural sensitivity approach*, the primary objective of this body of research has been to identify decision-making factors and cultural barriers to hospice use that are unique to African American patients so that they may be incorporated into campaign messages. In the opening chapter, I reviewed existing research on African Americans' hospice utilization and argued that there were three primary limitations of the current literature: (1) conceptualizing "culture" as a static entity, (2) ignoring the communicative, relational nature of decisions at the end of life, and (3) overemphasizing expert-driven, message-based approaches as the primary means of promoting hospice use. In response to these limitations, I drew upon the CCA and narrative theory to formulate four research questions and used ethnographic research methods to engage with 30 African American hospice patients and caregivers' hospice narratives. In this final chapter, I return to the limitations of the existing literature and summarize the principal contributions of this study. I then conclude the chapter by discussing the limitations of this study and offering suggestions for future research.

Looking Beyond Decision-Making Factors and Cultural Barriers

Previous studies have sought to identify decision-making factors and cultural barriers that influence African Americans' hospice utilization. In doing so, these studies have conceptualized hospice disparities as an individual-level problem that can be addressed by creating and disseminating culturally targeted hospice promotion messages (Kreuter et al., 2005; Parks & Kreuter, 2007). This approach is not unique to hospice utilization studies. According to Dutta and Basu (2011), the culturally-sensitive framework, where scholars isolate specific forms of health inequality (e.g., diabetes, cancer, etc.) and seek to promote specific health behaviors, such as cancer screening (Kreps, 2006) or eating healthy foods (Kreuter et al., 2005), constitutes the dominant ideology in health communication and disparities research (see also Dutta et al., 2013). While providing relevant hospice information in a culturally appropriate manner is an important and laudable goal, such an approach does not account for or address systemic issues that create and perpetuate disparities in the first place and, in isolation, may have limited impact in promoting health equity (Dutta, 2008; Dutta et al., 2013). Specifically, the conventions of the dominant approach “inadequately address the complexity with which structural racism” and national/organizational policies influence health disparities (Ford & Airhihenbuwa, 2010, p. S30; see also Dutta, 2008; Dutta & Basu, 2011; Castro & Singer, 2004).

Rather than being culturally-sensitive and, hence, isolating culturally specific decision-making factors including Christian spirituality, the importance of family caregiving, and preferences for aggressive treatment (e.g., Bullock et al., 2011; Enguidanos et al., 2011) as previous studies have done, the culture-centered focus of this

study draws attention to the role of structural violence in the formal health system in perpetuating inequity in hospice usage (Dutta et al., 2013; Farmer, 2003). The patients and caregivers who took part in this study noted how financial inaccess to formal medical services, discrimination by health care providers, and potential incongruences between hospice reimbursement policies and values/practices they associated with African American culture contribute to inequitable utilization of hospice services. The recognition of these structural barriers suggests a need for intervention efforts that reach beyond the provision of culturally targeted persuasive messages. Rather than focusing exclusively on individual-level solutions, such as message-based campaigns and/or communication training for providers, there is a need to “recenter” (Basu, 2011) efforts to address hospice disparities by enacting structural level changes. In particular, the results of this study call for interventions aimed at increasing access to medical care, working to eliminate discriminatory practices in health care contexts, and reconfiguring hospice reimbursement policies that force patients/caregivers to make the “terrible choice” of accessing hospice services or continuing with curative treatment (Casarett et al., 2009; Fishman et al., 2009). Thus, this study calls for a reformulation of hospice disparities research that foregrounds social justice and advocates policy shifts that promote greater equality in end-of-life care (Zoller & Dutta, 2008).

Centralizing Relational Communication in Making Sense of Hospice Care

The centrality of informal, relational communication in hospice decisions and making sense of experiences at the end of life is another important outcome of this research. Existing studies often stop at the point of identifying the factors (often positioned as cultural barriers) that African American patients and loved ones consider

when making hospice decisions. Further, like other medical decision-making research (Chen et al., 2003; Politi & Street, 2011), these studies tend to focus on formal sources of health information, particularly patient-provider communication (see Dillon et al., 2012; Yanchu et al., 2010). As evidenced by this study's results, current perspectives fail to account for the dynamic, communicative nature of hospice decisions as patients and their loved ones actively (re)create and share health/cultural meanings in their personal relationships.

By engaging with participants' stories from a culture-centered, narrative perspective, features of African American patients and caregivers' decisions about and experiences with hospice that are absent in the existing literature emerged. One such feature is participant's ability to assign new meanings to hospice care while working within the formal health system to access these services in ways that meet their contextual needs and fit with familial/cultural values. For example, by "playing along" with physicians and hospice providers while maintaining alternative understandings of hospice among family members and close friends, participants actively resisted biomedical discourses of scientific certainty and medical authority that dominate the United States' health system (Dutta, 2008). As Sharf, Harter, Yamasaki, & Haidet (2011) argue, health narratives "operate concurrently in relation to other stories, and may reinforce, indirectly compete with, or actively confront or resist one another" (p. 40; see also Lindemann-Nelson, 2001). By focusing on identifying factors and barriers, previous studies have ignored how these potentially resistive narratives shape patients/caregivers' hospice experiences. Furthermore, the existence/perceived need for these alternative narratives suggests a need to examine how discourses within and outside the formal

health system potentially limit access to hospice for individuals who may benefit from these services (Casarett et al., 2009; Fishman et al., 2009).

This study also follows previous hospice disparities research in highlighting the role of cultural identity in making sense of hospice care. Previous studies, however, have defined culture as static construct, where "the emphasis is on identifying stable characteristics on the basis of which cultures may be categorized and placed into boxes" (Dutta, 2008, p. 83). Consistent with the CCA, this study moves away from such constructions by conceptualizing culture as "continually shifting, dynamic, and open to change" (Dutta, 2008, p. 83). Even as participants identified some of the same cultural features or values as reported in previous studies, such as Christian spirituality, distrust of the health system, and preferences for family caregiving, the specific meanings that participants assigned to these features varied widely, as the meanings were negotiated in their personal relationships. Thus, while many of these cultural values have been described as "barriers" to hospice use in previous studies (Bullock et al., 2005; Campbell et al., 2010; Smith, 2004; Taxis, 2006), they actually served as the impetus for utilizing hospice care for many of the participants in this study. In other words, central to making decisions about hospice, or any other health care choice, is communication (i.e., the active, relational process of making and sharing meanings). By centralizing communication in sensemaking about hospice, this study highlighted the contested nature of cultural meanings and the impact of these divergent meanings in assigning meaning to end-of-life experiences. In Chapter 5, for example, narratives of regret largely centered on relational conflicts that emerged in relation to competing understandings of hospice

care and its role in caring for loved ones. Based on these findings, it is clear that sensemaking about hospice is a communicative process.

Promoting Hospice Care through Relational Health Advocacy

The findings of this study also highlight the need to move beyond expert-driven, message-based approaches to promoting hospice care among African Americans. Citing a mistrust of the health system and individual providers, a central theme in participants' hospice decision-making narratives was the act of going outside the formal health system in order to obtain information about hospice from trusted friends and family members. Additionally, participants also noted how they and others were already taking an initial step to spread the word about hospice care among other African Americans in the community through relational forms of health advocacy. From their perspective, these relational forms of advocacy allowed them to provide/obtain specific, contextual information about hospice care based on the first-hand experiences of a trusted person. From a practical standpoint, participants suggested ways of expanding the reach of their relational health advocacy efforts by holding workshops to inform/train surviving caregivers to advocate for hospice care within their social networks and partnering with local community organizations such as churches. They also suggested formalizing these efforts by developing a peer health worker program to promote hospice care and answer potential hospice patients' questions in person or over the telephone. The viability of these recommendations is currently being evaluated by a Quest workgroup that includes surviving caregivers, administrators, and frontline providers.

Limitations and Future Research

The primary limitation of this study has to do the participant sample. Given that the study relied on voluntary participants, there is a level of self-selection bias in the sample. Although this does not diminish the value of participants' narratives or perspectives, it was evident throughout the research process that individuals who volunteered to take part in the study were satisfied with the care they/a loved one received from Quest and were interested in helping a greater number of African Americans gain access to hospice care. It is noteworthy that while participants were extremely critical of the larger health system, in nearly 24 hours of interviewing, there were only three instances where patients or caregivers directly criticized Quest's care services. For example, Carl and Julia were dissatisfied that Quest did not immediately respond their request for a new Certified Nurse's Assistant when they felt the CNA "had no idea how to care for a Black person's hair" (field notes) while both Mandy and Charles criticized Quest for taking too long to refill their prescriptions. Apart from these three example, participants were overwhelmingly satisfied with Quest's care.

It is not extraordinary for patients and caregivers to express satisfaction with hospice care (see Connor et al., 2005; NHPCO, 2012), but it seems participants' perception of my affiliation with Quest may have played a role in their unwillingness to criticize the organization. Although I explained that I was not an official Quest employee (which was also documented in the study consent form), it was clear in many of the interviews that patients and caregivers viewed me as a representative of the organization. For example, in a number of interactions, participants used inclusive pronouns such as "you" or "y'all" when describing Quest. I reflect on this issue in my journal:

It is clear that many participants assume that I am a representative of Quest. Even as I tell them I am only collaborating with Quest to complete my dissertation study, I have an organizational ID badge hanging around my neck while we talk. I suppose this is a necessary part of the research process, since I would not have been unable to access this community without this partnership. Although it may influence the way they interact with me, it is also likely that many participants would have been unwilling to meet with me if they did not associate me with Quest.

As I note in this journal reflection, although my affiliation with Quest was necessary to gain access to the study sample, it also likely affected the stories patients and caregivers' chose to share with me. Given that they had or were continuing to receive hospice services from Quest, many participants may have felt the need to "perform" (Goffman, 1959) the role of grateful patient or caregiver, which may explain why there was limited criticism of Quest's care services.

An additional limitation of this study is the relatively small sample size. Although my goal was not to generalize to a larger segment of the population, a broader sample may offer perspectives and experiences that were not captured by this study. In particular, the "missing voices" in this study are hospice eligible African American patients and their caregivers who have chosen to continue with curative medical care after considering the hospice option. Future studies could attempt to include individuals who fall into these categories. Scholars could also explore the viability of longitudinal studies that follow patients and their family members across the continuum of care.

Finally, the primary objective for further study is exploring the process of implementing the recommendations for promoting hospice use among African Americans that emerged from this study and discerning the effect of these potential interventions over time. According to Dutta et al. (2013), a key challenge for projects is measuring the structural/interpersonal impacts of “CCA projects working on grassroots social change” (p. 177). Thus, my next step is to work with study participants and Quest in order to develop methods to measure the changes that may result from this study.

Conclusion

As Dillon et al. (2012) note, “death is often referred to as “the great equalizer,” [but] the care that individuals receive as they near the end of life serves as another example of the alarming health disparities between African American and white patients” (p. 189). Despite the limitations of this study, the results of this dissertation present an important step toward understanding and addressing disparities in hospice utilization. Drawing on the suggestions offered here, my hope is that more African Americans are able to make informed decisions about hospice enrollment and, thus, have the opportunity to access high-quality end-of-life care.

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Appendices

Appendix A: IRB Approval Letter



DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE
 Institutional Review Boards, FWA No. 00001669
 12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
 (813) 974-5638 • FAX (813) 974-5618

December 22, 2011

Patrick Dillon
 Communication
 University of South Florida
 4202 E. Fowler Ave., CIS 3058
 Tampa, FL 33620

RE: **Expedited Approval** for Initial Review
 IRB#: Pro00006661
 Title: African Americans and Hospice Care: Designing Culture-Centric Health Messages
 to Promote Informed Decision Making about End-of-Life Care

Dear Mr. Dillon:

On 12/21/2011 the Institutional Review Board (IRB) reviewed and **APPROVED** the above referenced protocol. Please note that your approval for this study will expire on 12/21/2012.

Approved Items:

Protocol Document(s):

[Research Protocol](#)

Consent/Assent Document(s):

[Consent Form.pdf](#)

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review categories:

- (5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis).
- (6) Collection of data from voice, video, digital, or image recordings made for research purposes.
- (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural

beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note, the informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on the form. Valid consent must be documented on a copy of the most recently IRB-approved consent form.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,



John A. Schinka, Ph.D., Chairperson
USF Institutional Review Board

Appendix B: Field Notes Sample

March 19, 2012 - Participant # 12 (Home)

1. Friend (mother had passed away) - last 2 weeks (liver cancer)
friend - medical technologist (voiced for it on 2 levels)
2. 5 yrs ago (84 yrs old)
2004 mother diagnosed with dementia; lived with mother in 2007
3. Thought it was only for terminal illness
4. Would not take mother for CT scan (finally did test)
5. Heard from friend; suggested hospice to mother's dr.
6. Dr. thought it was only for terminal illness (Dr. Warner)
7. Called hospice herself to check eligibility
8. Called hospital to hospice
9. Dr. said it was common not to have knowledge
10. Dr. pursued it herself; was "onboard"; relationship
11. Lots of people (no matter the ethnicity) do not know about hospice care; friend asked dr. about mother (Dr. refused)
12. Told co-worker to call himself
13. Nurse came out to visit
14. Several common questions to hospice nurse
15. In the beginning, pay an agency for almost \$20
16. Wanted to stay home (no nursing home)
17. Sister helped take care as well (feeding); both worked at night
supportive of decision
18. Out of state siblings "perplexed"; introduced siblings to nurse to explain
19. Would not have needed that; think they might like it
20. Ex. family member in Ms. mother also has dementia; can't get mother's docs to cooperate; "no idea what you are talking about" "I don't believe you"; Her own doctor couldn't believe it; Reform is a "wall"
21. Siblings problems - "stepped up to take care of her"
"You know what is going on"

Appendix C: Patient Interview Guide

Interview Guide - Hospice Patients

1. Could you tell me the story of how you got to the point where you felt that hospice was an option for you?
2. Tell me about your experiences since you have been a hospice patient.
2. When did you first learn about hospice? What initial questions did you have? Who answered these questions for you?
3. When did you begin considering hospice? What made you consider hospice at this time? Did you have any reservations about hospice? How did you overcome these reservations?
4. What role did others (i.e., family members, physicians) play in your decision? How did others react when you decided to enroll in hospice?
5. Are you happy with your decision about hospice? Is there anything you would change about your experiences? Would you recommend hospice care to others? Why/Why not?
6. How did your culture influence your decision to enroll in hospice? Why do you think African Americans are less likely to use hospice than whites are? What can be done to attract more African American patients?
7. If someone asked you about hospice, what would you say? What do other African Americans need to know about hospice to make an informed decision about it?
8. What is the best way to share this information with others?

Appendix D: Caregiver Interview Guide

Interview Guide – Hospice Caregivers

1. Could you tell me the story of how you got the point where you felt that hospice was an option for your loved one?
2. Tell me about your/your loved one's experiences with hospice.
2. What was your role in the decision-making process? Were you satisfied with your role?
3. When did you/your loved one first learn about hospice? What initial questions did you/your loved one have? Who answered these questions?
3. When did you/ your loved one begin considering hospice? What made you/your loved one consider hospice at this time? Did you/ your loved one have any reservations about hospice? How did you/ your loved one overcome these reservations?
4. What role did others (i.e., other family members, physicians) play in the decision about hospice? How did others react when your loved one decided to use hospice?
5. Are you happy with the decision about hospice? Is there anything you would change about the hospice experiences? Would you recommend hospice care to others?
Why/Why not?
6. How did your culture influence the decision to enroll in hospice? Why do you think African Americans are less likely to use hospice than whites are? What can be done to attract more African American patients?
7. If someone asked you about hospice, what would you say? What do other African Americans need to know about hospice to make an informed decision about it?
8. What is the best way to share this information with others?

About the Author

Patrick J. Dillon received his B.A.A. and M.A. in Communication from Central Michigan University. As a doctoral student, Dillon has earned numerous honors for his teaching and research. These honors include a Summer Research Fellowship from the National Cancer Institute and the Cancer Communication Research Center, the “Provost’s Commendation for Outstanding Teaching” from the University of South Florida’s Academy for Teaching and Learning Excellence, and the “Student Scholarship Award” from the Florida Communication Association. In addition to these honors, Dillon has also received research funding from the Center for Hospice, Palliative Care and End-of-Life Research and the College of Arts and Sciences at the University of South Florida. Dillon’s main areas of study include health communication, health disparities, and personal relationships. His research has been published in journals such as *Health Communication*, *Communication & Medicine*, *Journal of Family Communication*, *The Howard Journal of Communications*, and the *Southern Communication Journal*.