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AFRICAN AMERICAN CAREGIVERS' DECISION TO USE HOSPICE SERVICES FOR A LOVED ONE: A GROUNDED THEORY STUDY

by

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A DISSERTATION

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ABSTRACT

This qualitative grounded theory study explored the process of decision making for African American family caregivers in the southeastern United States, as they make hospice decisions for their loved ones. Although hospice use in the United States has grown over the last decade, a disparity continues to exist between African American and Caucasian populations. African Americans represent a small percentage of hospice users in the United States, despite research that has found that patients who use hospice experience improved symptom control, fewer unmet needs, and better end of life care. Research has identified many reasons for this disparity; however, little is known about the decision-making process of African Americans who choose hospice care.

The purpose of this qualitative study was to understand the decision-making process to use hospice services, from the African American family caregiver perspective. Individual, in-depth, semistructured interviews were conducted with 18 African American family caregivers. Interview data were analyzed using a grounded theory approach.

Results showed that realizing that their loved ones were at the end of life was at the core of the decision-making process for these caregivers. Caregivers needed to come to this realization in order to make the decision to use hospice care. Physician communication was integral to the process because physicians were the primary clinicians to introduce the caregivers to their loved ones’ prognoses and to the hospice option as the next step in care. Many factors were considered when making the decision but most important to caregivers was their loved ones' comfort.

The results of this study illustrated the need for better understanding of the process of realization of dying that African Americans caregivers go through during end of life decision making. The results highlight the importance of the communication of healthcare personnel, specifically physicians, during this critical decision-making process for African American caregivers.

Keywords: African American, hospice, end of life, caregivers, decision-making

DEDICATION

I dedicate this dissertation to the memory of my parents, Grenville and Doris Gordon. My father, who never went to college, instilled in his children the importance and value of education. I know he is well pleased with this accomplishment. My mother spent 50 years as an educator; her answer to anything that ailed us was, “Take a course.” She saw me start this PhD journey and make it almost to the end, but unfortunately did not live to see me finish. One of our last conversations was about my PhD journey, her words to me were, “I know it’s hard, but you must finish it.” I reflected on those words as I faced the challenges completing this journey. Thank you both for giving me the strength to finish. This dissertation is dedicated in your honor.

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I thank my family for their undying support and encouragement throughout this journey: my daughter, Brittley Kristina, for her quiet support and understanding; my sisters and brothers for their belief in me and for their constant encouragement over the years. A very special thanks to Luke for enduring with me and believing in me through all these years, thank you for understanding when school came first. Thank you to my amazing group of sister friends Drs. Dawn Aycock, Kenya Kirkendoll, and Joan Cranford—you have literally and figuratively carried me through this program; Lisa, Sharon and Monica, your support meant the world to me. Thank you to my Georgia State University family for your support through the years.

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Lastly, I acknowledge those who participated in my dissertation research. This study would not have been possible without their willingness to share their experiences with such a difficult subject. I hope that the results of this study will help to inform interventions to make end of life discussions and decisions easier for others.

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LIST OF ABBREVIATIONS

AA	African Americans
ACS	American Cancer Society
CDC	Centers for Disease Control and Prevention
CG	Caregiver
EOL	End of life
HCP	Healthcare personnel
IOM	Institute of Medicine
NHPCO	National Hospice and Palliative Care Organization
NINR	National Institute of Nursing Research
PI	Principal investigator

CHAPTER 1

INTRODUCTION

The decision to use palliative and hospice services is complex, requiring the collaboration of patients, families, and healthcare professionals. While the use of palliative and hospice services has increased over the years (National Hospice and Palliative Care Organization [NHPCO], 2015), historically patients, family members, and clinicians have been reluctant to employ palliative and hospice services early and in all patients who could benefit (Institute of Medicine [IOM], 2014). This reluctance has included factors such as personal values about disease treatment, the uncomfortable nature of the palliative care conversation, preference for the prolongation of life sustaining treatment, a feeling of failure, and lack of knowledge of palliative and hospice services (Hill, 2010; Melvin, 2010; Melvin & Oldham, 2009).

However, an increasing number of healthcare providers, patients, and family caregivers recognize that palliative and hospice services have a wider use than improving the quality of death of patients (Brooksbank, 2009; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2008; Teno et al., 2011). When received early, alongside standard medical care for patients with serious illnesses like cancer, palliative services can improve care and quality of life for patients and family members (Bakitas et al., 2009;

Bakitas et al., 2015; Dionne-Odom et al., 2015; Parikh, Kirch, Smith, & Temel, 2013). A change in perception of palliative and hospice services is evident in the increased use of hospice and the number of palliative care programs. Hospice use increased from one million people in 2004 (NHPCO, 2008) to 1.7 million in 2014 (NHPCO, 2015). The number of palliative care programs in U.S. hospitals with more than 50 beds increased from 53% in 2008 to 67% in 2015, and 90% of hospitals with 300 beds or more offered palliative care services (Dumanovsky et al., 2016; Hughes & Smith, 2014).

Palliative care is a model of care focused on improving the quality of life for patients and families (Clinical Practice Guidelines for Quality Palliative Care, 2013). Palliative care is provided by an interdisciplinary team of nurses, physicians, social workers, chaplains, and others; it is a holistic model of care provided throughout the patient's illness that allows the patient and family to make informed decisions about care. Palliative care can be implemented along with treatments intended to extend life; however, it neither accelerates nor delays death (Clinical Practice Guidelines for Quality Palliative Care 2013; World Health Organization, 2015).

Hospice is one care model used to deliver palliative care; it is generally implemented in the home or a specialized facility for patients who are in the late phase of a life limiting illness (Centers for Disease Control and Prevention [CDC], 2011). Hospice incorporates palliative care principles of holistic, comprehensive, interdisciplinary care through the end of life, including bereavement (Mazanec, Daly, & Townsend, 2010; Spruill, Mayer, & Hamilton, 2013). Hospice care is provided in lieu of life prolonging therapies, and per Medicare guidelines is reserved for patients with 6 months or less prognosis if the disease was to follow its normal course (CDC, 2011).

Role of Family in End of Life Decision Making

Decision making at the end of life is complex. Near the end of life with a chronic illness, family members or significant others often assume the role of informal primary caregiver and possibly decision maker (Braun, Beyth, Ford, & McCullough, 2008; Campbell, Williams, & Orr, 2010; Huang et al., 2012). As the patient’s condition progresses, family caregivers may serve as primary decision makers, which may be a legal designation (Braun et al., 2008; Huang et al., 2012). Family members may find the decision-maker role at the end of life complicated and maybe even burdensome, due to factors related to ethics, finances, lack of palliative care knowledge, and negative attitudes towards palliative care (Huang et al., 2012).

For African Americans, the decision-making role in healthcare and other decisions is shared among family members (Campbell, Williams, & Orr, 2010; Mazanec et al., 2010). These decisions are made within the context of cultural considerations, which for African Americans may include greater emphasis on spirituality, mistrust of the healthcare system, and a greater preference for aggressive treatment, which can add to the complexity of the decision-making process, particularly at the end of life (Huang et al., 2012; Johnson, Kuchibhatla, & Tulsky, 2008; Welch, Teno, & Mor, 2005).

Schubart, Farnan, and Kass (2015) examined African American women’s breast cancer surgery decisions and found that family and friends who had experienced breast cancer were the most trusted source of information in the decision-making process. Jones, Steeves, and Williams (2010) explored rural African American men’s decision to get prostate cancer screening and found that the influence and impact of family and friends were of utmost importance and had a considerable impact on the decision to seek prostate cancer screening. Yet another study, exploring colorectal cancer screening beliefs among urban African Americans, showed a significant relationship between family support and positive colorectal cancer screening beliefs (Brittain, Loveland-Cherry, Northouse, Caldwell, & Taylor, 2012).

The important influence of family in decision making among African Americans is also present in end of life decisions. Waters (2001), in a study exploring African American end of life care planning and decision making, found that a trusted family member, friend, or pastor was a preferred choice to make end of life care decisions. Yancu, Farmer, Graves, Rhinehardt, and Leahman (2015) explored attitudes toward end of life care and found that African American participants believed hospice was a feasible option when family members and loved ones agreed. Lastly, 61% of respondents in a study exploring hospice access and use by terminally ill elderly African American patients reported the involvement of family in their decision to use hospice services (Noh & Schroepfer, 2015).

While family members are involved in decision making, it may not be without disagreements. Patient and family members have been found to differ on opinions, with hospice care being one area of disagreement (Zhang & Siminoff, 2003; Zhang, Zyzanski, & Siminoff, 2010). In studies examining family disagreements about treatment decisions in patients with lung cancer, family caregivers and patients disagreed on the discontinuation of treatments, choice of doctors, quality versus quantity of life, caregiving, and use of hospice care (Siminoff, Dorflinger, Agyemang, Baker, & Wilson-Genderson, 2012; Zhang & Siminoff, 2003; Zhang et al., 2010). Caregivers were more than twice as likely to report disagreements even when patients did not (Siminoff et al., 2012). African Americans were not well represented in these studies. However in one study that did compare ethnic differences in caregivers, African American caregivers (*n* =

26) were less likely than Whites (*n* = 173) to be satisfied with their involvement in treatment decisions (Zhang, Zyzanski, & Siminoff, 2012).

Although it is evident that the involvement of family members in decisions and treatment of those with life limiting illnesses is important, understanding how family members make decisions, especially in African Americans remains unclear. Family caregivers play an important role in the hospice care model. Thus, the exploration of decision making including areas of disagreement, using a sample of African American family caregivers helps us better understand the process and lays the ground work for future interventions to facilitate decision making at the end of life in this population.

Statement of the Problem

Of the 1.7 million patients who received hospice services in the United States in 2014, 76% were Caucasian and 7.6% were African American; a decrease in African American use from 9% in 2007 (NHPCO, 2008, 2015). It is important to note that the percentage of African Americans using hospice services is considerably lower than the representation of African Americans in the general population, which in 2014 was 13.2% (U.S. Census Bureau, 2017). The small percentage of African Americans using hospice, and the disparity when compared with Caucasians, can be attributed to many factors. A preference for aggressive treatment at the end of life (Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009; Johnson et al., 2008; Rhodes, Batchelor, Lee, & Halm, 2015; Welch et al., 2005), spiritual beliefs, cultural beliefs, disparate healthcare (Mazanec et al., 2010), mistrust of the healthcare system (Johnson et al., 2008), and a lack of knowledge (Rhodes et al., 2015) are all factors prevalent in the African American community that contribute to hospice use.

The disparity in hospice use between African Americans and Caucasians exists even though the literature indicates that patients who use hospice services experience improved quality of dying, fewer unmet needs at the end of life, and better symptom control (Kiely, Givens, Shaffer, Teno, & Mitchell, 2010; Teno et al., 2011). Furthermore, a 2009 study found that hospice patients reported greater satisfaction with communication of healthcare personnel and better overall satisfaction with medical and nursing care than in an acute care setting (Addington-Hall & O'Callaghan, 2009). Hospice use has also been shown to decrease the use of costly services such as the emergency room and intensive care unit (Carlson et al., 2010).

Significance of This Study

The importance of hospice and palliative care has been addressed by nationally recognized organizations in their guidelines or strategic plans. These organizations include the National Institute of Nursing Research (NINR), the American Cancer Society (ACS) and the Institute of Medicine (IOM). The strategic plan of the NINR (2011) stated that research efforts should seek to improve understanding of the complex issues and choices underlying palliative and end of life care. Also included is the idea that palliative and end of life interdisciplinary research efforts should apply behavioral, biological, and social science strategies to better understand and address the challenges faced by individuals with life threatening illnesses and their caregivers (NINR, 2011). The ACS (2015) stated that it has expanded its definition of palliative care over the years to include management of side effects, pain control, and other issues facing cancer patients at all stages of cancer treatment and after treatment, not just at the end of life. As a result, the ACS funded more than $26 million in quality of life and cancer survivorship research and recommended that established knowledge and new research findings about palliative care cancer prevention and treatment be applied extensively to the American population to improve the quality of life of patients with cancer. Lastly, in the IOM (2014) report, an expert panel argued that improving the quality and availability of medical and social services at end of life could improve quality of life and potentially contribute to a more sustainable health system. This study addressed the objectives and goals of these organizations by improving our understanding of the issues surrounding African Americans' decision making as it relates to the use of hospice services.

Understanding the issues surrounding African American decision making to use hospice is particularly important, because African Americans are more likely than Caucasians to die from the complications of illnesses such as heart disease, diabetes, dementia, and certain types of cancer (CDC, 2010). Consequently, one can surmise that African American patients and families are often faced with important end of life care decisions, such as the decision to use hospice services, yet only a small percentage choose this option. Despite this, there is a lack of research involving African Americans who do use hospice services. Therefore, it is unclear how African Americans who choose the hospice option overcome their concerns. Little is known about the factors that guide their decision to choose hospice care. This research study adds to that body of knowledge and improves our understanding by providing a model that explains the process of the decision making of African American families who choose hospice. The findings from this study can inform policy and practices of healthcare personnel as they work with African American families at the end of life.

Purpose of the Study

The purpose of this qualitative grounded theory study was to understand the African American decision-making process to use hospice care services from the perspective of the family caregiver. The study was conducted in the southeastern United States.

Specific Aims

The aims of the study were to (a) identify the factors involved in the decision-making process of African American family caregivers who use hospice services for a loved one and (b) develop a substantive theory of the decision-making process of African American family caregivers who choose hospice services for a loved one.

Research Questions

A central research question and five subquestions guided this study:

What is the decision-making process for African American family caregivers to use hospice service for their loved one?

1. What is at the core of African American family caregivers' decision-making process to use hospice services for a loved one?
2. What factors assist or impede African American family caregivers in their decision to use hospice services for a loved one?
3. What resources do African American family caregivers employ in their decision to use hospice services?
4. What is the role of the African American family caregiver in the decision-making process to use hospice services?

5. What is the theoretical model that explains the decision-making process of African American family caregivers' decision to use hospice services for their loved one?

Theoretical Framework

The grounded theory methodology is not guided by theory but instead seeks to generate theory. Therefore, the theoretical concepts of Andersen's behavioral model of health services use for vulnerable populations were loosely applied to inform the interview questions used in this study. The model includes three major concepts: (a) population characteristics, (b) health behavior, and (c) outcomes (Gelberg, Andersen, & Leake, 2000). These concepts were congruent with many of the variables found in the literature that influenced the African American patient and family's decision to use hospice services.

Definition of Terms

African American. Person who self-identifies as African American.

Axial coding. A process in grounded theory analysis that creates a coding paradigm that illustrates the link between codes through conditions, strategies, and consequences (Creswell, 2013).

Caregiver. An individual who self-identifies as an informal caregiver (any unpaid relative, partner, or friend) who is involved in care and decision making of the care recipient.

Categories. Concepts found to pertain to the same phenomena (Corbin & Strauss, 1990).

Conditional matrix. A diagram that presents how micro and macro factors involved in the process affects the core phenomenon (Corbin & Strauss, 2015).

Constant comparative method. A method used in grounded theory studies that entails the comparison of various parts of the data against each other for similarities and differences (Corbin & Strauss, 2015).

Core phenomenon. A concept that is broad enough that it encompasses the main ideas expressed in a study (Corbin & Strauss, 2015).

Dimensions. The dimensions of a property show the continuum over which a property can vary (Creswell, 2013).

Grounded theory. The process of discovering theory from data that is systematically obtained and analyzed (Glaser & Strauss, 1967).

Open coding. Initial stage of grounded theory data analysis where data are reviewed and placed into categories of information (Creswell, 2013).

Properties. The attributes of a concept that give it definition and distinguish it from other concepts (Strauss & Corbin, 2015).

Propositions. Statements that show the relationship between categories in the model developed through grounded theory analysis.

Saturation. In grounded theory, this is the process of fully developing a concept as it relates to its properties and dimensions (Corbin & Strauss, 2015), or to the collection of enough data to fully develop a model (Creswell, 2013).

Selective coding. The final process of grounded theory analysis in which categories are interrelated in the model through hypotheses developed from the coded data (Creswell, 2013).

Theoretical sampling. A method of data collection used in grounded theory, where the researcher decides what further data to collect, based on the concepts that are being developed (Corbin & Strauss, 2015).

Summary

While the reasons for underutilization of hospice services by African Americans are well documented, little is known about the decision-making process of those who choose this option. Understanding this decision-making process is a necessary first step in reducing disparities in care for African Americans at the end of life. This study used a grounded theory approach to explore the decision-making process and thus addressed an important gap in the literature. The grounded theory approach allowed for the emergence of theory that was grounded in the participants' experiences. The derived theory provides a realistic foundation for interventions and future research, which can assist African Americans in making informed decisions about care at the end of life.

CHAPTER 2

REVIEW OF THE LITERATURE

Multiple healthcare decisions with varying dimensions of complexity need to be made during a time of illness. Patients are thrust into unfamiliar territory related to both treatment and personnel and often are not in optimal health to be making complex decisions. Therefore, they may rely on others for assistance in making decisions. The decision-making process is further complicated by the values, beliefs, and history brought by the patient, family, and healthcare providers. African Americans disproportionately suffer from chronic diseases and life limiting illnesses such as heart disease, diabetes, renal disease, early stroke, and certain types of cancers (CDC, 2013). They are therefore more frequently faced with the need to make healthcare decisions. The difficult decision-making process is further compounded for African Americans, since they often present for healthcare in the advanced stages of disease; a time when decision making becomes critical (Stringfellow, 2013).

Decision making at the end of life becomes even more complex given the sensitive nature of the potential loss of an individual's life or the loss of a loved one. Patients and families are often faced with the decision of whether or not to continue curative treatment, and at some point in the decision-making process, a discussion of the need for hospice care may arise. In 2014, 1.7 million persons received hospice services in the United States; 59% of these patients received care in their homes, 32% in a hospice care facility, and 10% in an acute care facility (NHPCO, 2015). Also in 2014, 84% of the patients receiving hospice care were over the age of 65 with the largest concentration (41%) being 85 years and older; 63% of these patients had non-cancer diagnoses with cancer diagnoses accounting for the remaining 37% (NHPCO, 2015). Thirty six percent of patients spent 7 days or less in hospice care from the time of admission to either death or discharge (NHPCO, 2015). On further examination of the types of patients receiving hospice care, the NHPCO report stated that of the 1.7 million patients receiving care in 2014, 76% were Caucasian compared to only 7.6% African American. Hospice use in the United States has increased over the last decade, from just over 1 million in 2004 to 1.7 million in 2014 (NHPCO, 2015). Despite this growth, a disparity continues to exist in hospice use between African Americans and Caucasians.

The purpose of this literature review was to provide an appraisal and synthesis of the state of the science related to palliative and hospice decision making within African American families. The literature review provided important background on African American (AA) hospice decision making and identified gaps in the literature that supported the need for this study. To address gaps in the literature about African American decision making surrounding hospice use, a broader view was conducted by first examining the literature related to African American healthcare decision making in general, before narrowing the review to decision making surrounding hospice as it related to this study. Families dealing with palliative care and hospice decision making often do so following the illness of a loved one. Therefore, to ensure further relevancy of the current study, the focus of the African American healthcare decision making literature review was concentrated on studies related to decision making surrounding illness.

This literature review examined African American healthcare decision making in general and specific to palliative and hospice decision making. Each section delineates the method used to conduct the search and extract data, the factors that influence the decision-making process, and the decision-making frameworks used to guide the design of the studies or generated from the studies. Each section is summarized. Commonalities of the two sections are then summarized. A description of the conceptual framework chosen for this study is also included.

African American Healthcare Decision Making

A systematic literature search was conducted on African American healthcare decision making. The inclusion criteria for the articles included (a) written in English, (b) published between January 2005 and June 2016, (c) original research, (d) included African American or Black adults 18 years and older, and (e) included decision making related to illness of themselves or their loved ones. Studies were excluded if decisions were not related to illness or disease; that is, studies focused on decision making for health screenings (e.g., mammograms, prostate cancer screening) or other reasons related to healthcare, or were dissertations, books, magazines, or conference proceedings.

Queries were conducted in CINAHL Plus, MEDLINE, and PsychInfo databases. Search terms included *African American*, *Black*, *healthcare, medical*, *illness, disease,* and *decision making*. In the initial research, the researcher identified 738 articles. Ten articles met the inclusion criteria. Figure 1 is a flow diagram depicting the inclusion and exclusion criteria of the articles selected for this section of the literature review.

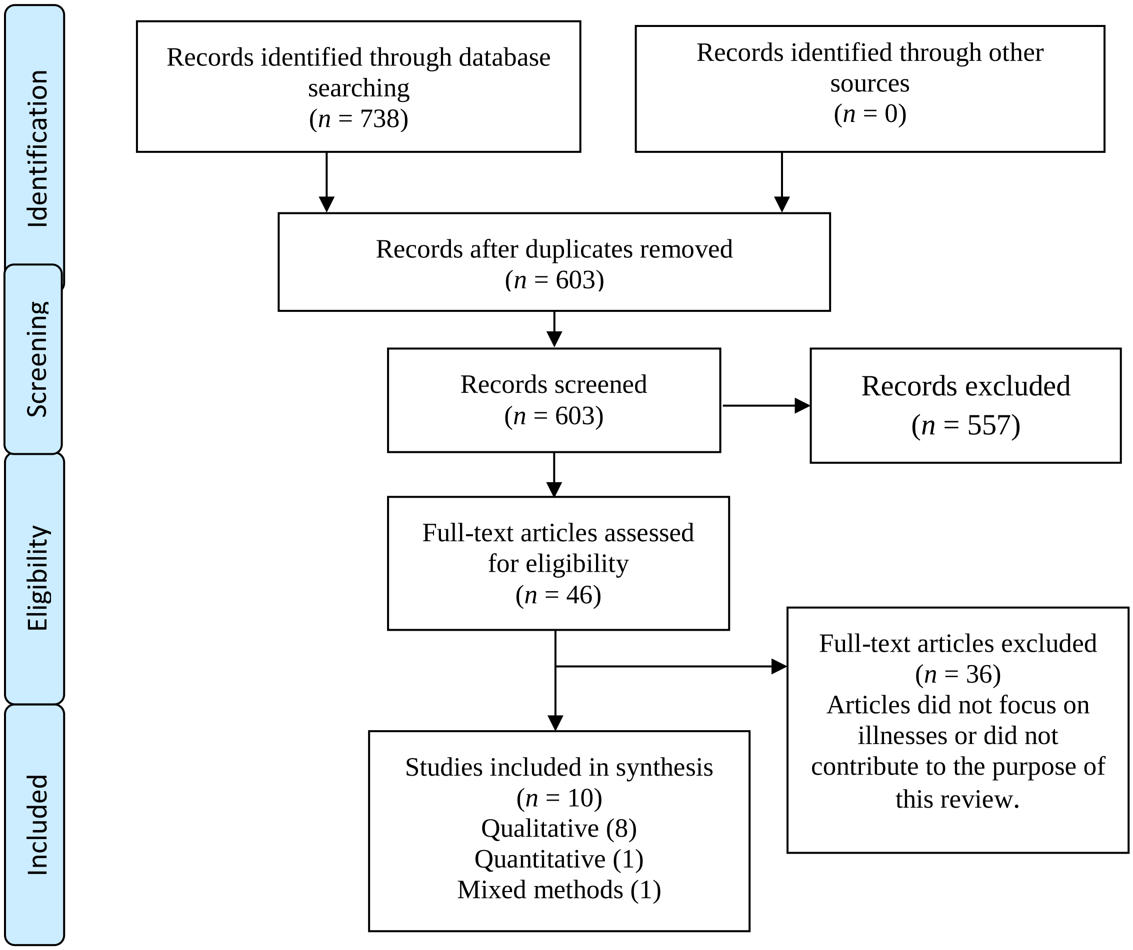


Figure 1. Inclusion-exclusion of articles flow chart for African American healthcare decision making. Adapted from "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement" by D. Moher, A. Liberati, J. Tetzlaff, amd D. G. Altman, 2009, *PLoS Med, 6*(7), e1000097. doi:10.1371/journal.pmed1000097

A literature matrix table was created to organize, review, and synthesize the articles that met inclusion criteria. The table includes the following headings: (a) authors, title, and journal; (b) purpose or research questions; (c) study methodology and design; (d) sample size and characteristics; (e) findings; and (f) decision-making models, used if any (See Appendix A). Through the review process, factors influencing healthcare decision making of African Americans and the use of decision-making frameworks were identified and served to organize the results of the review.

Factors Influencing Healthcare Decision Making of African Americans

The complex task of healthcare decision making is influenced by several individual and social factors. Patients may choose to make decisions in isolation solely based on the information they receive, while others may choose to consult with family, friends, or healthcare personnel (Broadstock & Michie, 2000). From the literature review, various factors were noted to influence African American decision making; however, three of those factors were recurrent: (a) family and friends, (b) mistrust of the healthcare system, and (c) patient-physician communication and relationship.

Involvement of Family and Friends in African American Healthcare Decision Making

For African Americans, family, which can include both blood relatives and extended family, plays an important part of many life changing decisions (Campbell et al., 2010; Mazanec et al., 2010). As a source of information, family and friends who experienced breast cancer were found to be the most trusted source of information in a qualitative study exploring breast cancer surgery decisions among 14 African American women (Schubart et al., 2015). In a study examining prostate cancer survivors treatment decision making, 44% of African American men (n = 181) used family and friends as a source of information (Palmer, Tooze, Turner, Xu, & Avis, 2013). In another qualitative study exploring breast cancer treatment decisions, one participant stated that her husband was the one who did the research and provided her with reading materials that assisted in her understanding of the disease (Sheppard, Adams, Lamdan, & Taylor, 2011). In yet another study, women making the decision to go to the hospital when experiencing acute myocardial infarction symptoms gathered information from family members and friends before making the decision to seek medical attention (Harralson, 2007).

African American patients also considered a history of disease and treatment choices in their families, when making decisions related to their disease and management of that disease. Participants in a study exploring barriers and facilitators to shared decision making in patients with diabetes, expressed that their knowledge and motivation to avoid complications came from prior exposure to family members with diabetes (Peek et al., 2009). Sheppard et al. (2011), in a study of 49 African American women with breast cancer, found that women chose more aggressive breast cancer treatment based on the experiences of disease recurrence in other family members who chose less aggressive treatment. Palmer et al. (2013) divided 181 African American men into categories of active, passive, and collaborative decision makers. Active decision makers preferred to make the final decisions about the treatment they received, passive decision makers preferred that their physician make the final decision, and collaborative decision makers preferred to share the responsibility of the final decision with their physician (Palmer et al., 2013). In comparing the three categories of decision makers, the active decision makers scored the choice of *knowing people who were satisfied with their treatment* higher when asked about the reasons for their choice of treatment (Palmer et al., 2013). In contrast, Harralson (2007) found, in a study of women who experienced acute myocardial infarction symptoms, the belief that one could not have an acute myocardial infarction, thus increasing the odds of a delay in treatment. This occurred even though 84% of the women had a family history of heart disease.

Family was also seen as a source of support to African American patients making healthcare decisions. Women making breast cancer treatment decisions reported that family members were a source of emotional and tangible support (Sheppard et al., 2011). Family members and friends attended physician visits with patients, asked questions of the physicians, made notes to assist the patients in decision making, encouraged them, and even took them to seek medical attention when necessary (Harralson, 2007; Hopp, Marsack, Camp, & Thomas, 2014; Lee, Marks, Sanders, & Wiebe, 2016; Schubart et al., 2015; Sheppard et al., 2011).

These findings indicated that family and friends were involved and are important members in the process of healthcare decision making for African Americans. However, little detail is provided about exactly how they were involved in the decision-making process. The current study included questions and/or probes that explored the role of family and friends in decision making and how they fit in the process. The inclusion of family and friends can assist in informing interventions that can positively influence the healthcare decision making of African Americans.

Mistrust of the Healthcare System and African American Healthcare Decision Making

Mistrust of the healthcare system in the African American community is a problem rooted in history and has affected all aspects of health and healthcare among African Americans and was evident in the literature. Mistrust was reported in the form of physician communication with patients, particularly physicians' demeanor during patient encounters, and the perceived accuracy of the information given to patients (Peek et al., 2013; Peek et al., 2009; Waite, 2008). In a phenomenological study of 51 African Americans with diabetes, one participant reported, "The doctor came in the room speaking in a very condescending manner…it was his tone of voice and his mannerisms…I'm sure if we were a different race the doctor probably would have been different" (Peek et al., 2013, p. 619). A lack of trust in the physicians' understanding of the African American race and hence a mistrust of the appropriateness of the treatment regimen was reported (Peek et al., 2013; Peek et al., 2009; Waite, 2008).

African Americans also expressed mistrust regarding medications and the use of medical devices suggested as a part of treatment by physicians. When examining factors important in treatment decisions in women with breast cancer, participants reported a mistrust of chemotherapy medications suggested by their physicians, even after reading all of the material provided (Sheppard et al., 2011). Waite (2008) found a similar mistrust from participants seeking treatment of depression when prescribed medications for their disease. Women considering reconstructive surgery for breast cancer reported a mistrust of the implants that would be used (Rubin, Chavez, Alderman, & Pusic, 2013). The reason for the mistrust of medication and particularly for the use of medical devices was explained by participants as a fear of being used as experimental subjects (Peek et al., 2013; Rubin et al., 2013). These participants made specific reference to the Tuskegee syphilis study and being used as experimental subjects when explaining their heightened mistrust of physicians and the suggested use of any medications or medical devices as a part of their treatment (Peek et al., 2013; Rubin et al., 2013).

Trust in healthcare personnel is paramount in the decision-making process of all patients. Physicians and other providers must understand the legacy of disparate treatment that African Americans bring to a healthcare situation. This legacy provides the lens through which some African Americans see the patient-provider relationship. Healthcare providers must therefore make special efforts to create a trusting relationship with these patients by addressing their own implicit biases, showing respect for patients and families, providing patients with the necessary and appropriate information, and allowing patients the necessary time and freedom to ask questions and voice concerns.

Patient-Physician Communication and Relationship

Patient-physician communication is an essential component of healthcare decision making, yet this review indicated that physicians were less than effective in their communication with African American patients. Patients reported feeling a lack of power when communicating with their physicians; an inequity attributed to race; "African Americans are scared to speak up and ask questions and voice their opinions" (Peek et al., 2009, p. 1137). Patients also reported physicians' lack of transparency and an avoidance of information sharing, "Well the doctor don't tell me much…I have to bring it out of the doctor…What's the matter with me? And how am I doing? You don't get all the information you should have" (Lee et al., 2016, p. 157). Even when physicians gave information, their use of unfamiliar medical language was a hindrance to communication (Lee et al., 2016). This was compounded by patients' reluctance to admit their lack of understanding during these meetings (Lee et al., 2016).

Other researchers discovered that even though patients thought they received adequate information to make decisions, there was important information missing that was necessary for the understanding of prognosis, outcomes, and decision making (Lee et al., 2016; Sheppard et al., 2011). African American women making breast cancer treatment decisions reported not knowing specific information about their disease, such as the type of cancer, the stage, lymph node involvement, and estrogen receptor status (Sheppard et al., 2011). This type of information is necessary to make a truly informed decision about treatment.

The patient-provider relationship is a key component in healthcare decision making. The findings of this review indicated that some relationships were such that physicians presented treatment options and patients chose one (Lee et al., 2016; Peek et al., 2009; Sheppard et al., 2011). The relationships did not appear to be ones involving mutual discussions in which patients were able to ask questions and physicians entertained discussions before a mutual decision was made (Lee et al., 2016; Peek et al., 2009; Sheppard et al., 2011). Peek et al. (2013) reported that patients explained this as deferring to the authority and expertise of their physicians. Forty-two percent of participants (*n* = 181) stated that they made the final decisions about their prostate cancer treatment; however, there was substantial consideration of their physician's opinion; 38% reported that they shared the responsibility of decision making with their physician. An interesting result of the Peek et al. study was that the participants who identified as having a passive role in their prostate cancer decision-making process reported a better quality of life compared to the patients who had an active role.

Patient-physician communication is vital to healthcare decision making of any patient. However, this communication is more important in the African American community because of the history of mistrust of healthcare providers. Physicians must be clear and forthcoming with all information and communication to ensure that African American patients have the information necessary to make the best decision. Appropriate communication also builds a trusting relationship between patients and physicians necessary for the decision-making process. This review of the literature about decision making in African Americans with various illnesses, provided some insight into the most common factors that influence African American healthcare decision making. While these factors are important influences on the decision-making process, what remains unclear in the literature is the actual process used and how these factors fit into African Americans' healthcare decision-making process.

Decision-Making Frameworks Used to Examine African American Healthcare Decisions

Of the 10 articles reviewed related to African American healthcare decision making, only two discussed the use of theoretical frameworks to explain African American healthcare decision making. Peek et al. (2009) used a combination of constructs from the Charles model, the theory of planned behavior, and the ecological model to develop the interview guide used in their study that explored patient trust in physicians and shared decision making among African Americans with diabetes. The study findings resulted in a new model that showed that race/culture influenced patient trust of physicians in the areas of interpersonal relationships and technical skills (Peek et al., 2013). Race/culture influenced shared decision making in the areas of information sharing and decision making. The model also revealed that patient trust directly affected shared decision making (Peek et al., 2013).

Sheppard et al. (2011) did not report the use of a framework in their study design, but instead adapted Bastian's adherence model to frame the results. The adherence model has the construct of the art of care added to the existing constructs of the health belief model (Sheppard et al., 2011). Sheppard et al. explored the sociocultural factors important to Black women's breast cancer diagnosis and treatment decisions and the healthcare related factors influencing treatment decisions. They found that factors such as family relationships, spiritual beliefs, shared decision making, and patient-provider communication all fit within the domains of the adherence model (Sheppard et al., 2011).

Harralson (2007) used the self-regulatory model to frame the interview of participants in a study that examined the factors that influence the delay in seeking treatment for acute ischemic symptoms. Harralson's population was predominantly African American lower income women. The self-regulatory model was used to explain symptom representation and decision-making behaviors that occur in response to symptoms (Harralson, 2007).

The use of a decision-making framework was not common in studies that explored healthcare decision making among African Americans. More evident is the absence of a theory or framework being generated from the data collected to explain the decision-making process of African Americans' healthcare decision making. This indicates a need for more research in this area and the need for the current study.

African American Palliative and Hospice Care Decision Making

Another literature search was conducted on the decision-making process of African Americans surrounding palliative care and hospice services. Inclusion criteria included (a) written in the English language, (b) published between January 2005 and June 2016, (c) original research, (d) included only adults 18 years and older, and (e) involved African Americans and palliative care or hospice decision making. Dissertations, books, magazines, and conference proceedings were excluded. Also excluded were articles focused on decision making surrounding advanced directives.

Queries were conducted in CINAHL Plus, MEDLINE, and PsychINFO databases. Search terms included *African Americans, Blacks, decision making*, *palliative care,* and *hospice care*. One hundred and sixty-one articles were identified in the initial search with an additional five obtained from other sources. Sixteen articles met inclusion criteria and were used in the review. Figure 2 is a flow diagram illustrating the inclusion and exclusion criteria of the articles selected for this second literature search.

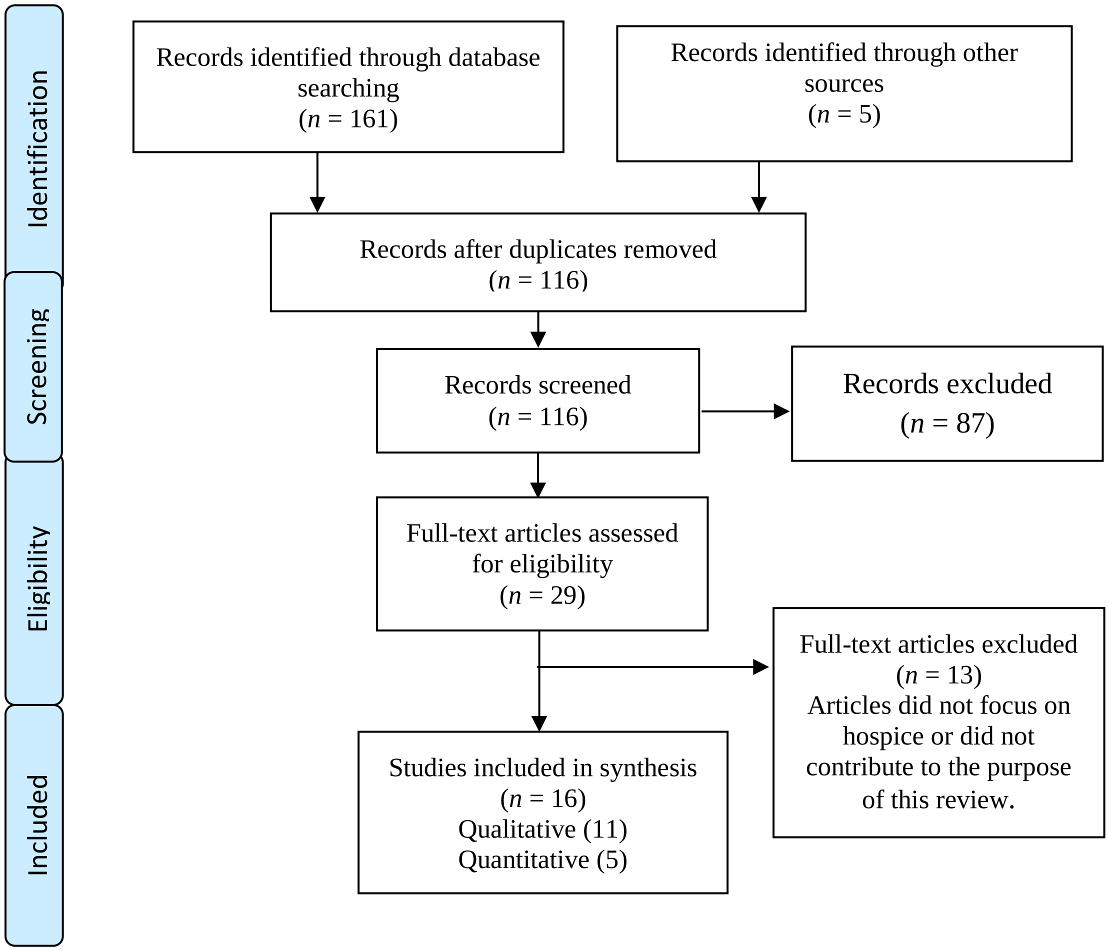


Figure 2. Inclusion-exclusion of articles flow chart for decision-making process of African Americans surrounding palliative care and hospice services. Adapted from "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement" by D. Moher, A. Liberati, J. Tetzlaff, amd D. G. Altman, 2009, *PLoS Med, 6*(7), e1000097. doi:10.1371/journal.pmed1000097

A similar literature matrix was created to organize, review, and synthesize the articles that met criteria (See Appendix B). A review of the literature of African American palliative care decision making revealed that palliative care decision making among African Americans, is framed through decisions surrounding use of hospice services. Hospice is one of the vehicles through which palliative care is delivered.

Factors in African Americans' Decision Making Surrounding Palliative and Hospice Care

A review of the selected articles revealed that the recurring factors influencing hospice decision making in African Americans were similar to those in the general decision-making articles reviewed. These factors were religiosity, mistrust of the healthcare system, knowledge of hospice services, and family.

Influence of Religiosity in Decision Making about Hospice

Following emancipation, African Americans were able to build their own religious communities in churches and hold positions of leadership that were otherwise not possible (Giger, Appel, Davidhizar, & Davis, 2008). The church family therefore became an important component of African American culture and has consistently served as a source of empowerment and support in every aspect of life, especially during illness (Holt & McClure, 2006; Mazanec et al., 2010). The prevailing theme in the African American church is that God is in control and only he can decide life or death (Campbell & Ash, 2007; Campbell et al., 2010; Johnson, Elbert-Avila, & Tulsky, 2005; Torke, Garas, Sexson, & Branch, 2005). For some African Americans, end of life decisions, like hospice care, may appear as a paradox as they subscribe to the belief that God is in control of life and death, while depending on manmade medical care to fight disease and prolong life (Campbell & Ash, 2007; Torke et al., 2005). This paradox may be explained by the belief that because God is in control, it is incumbent upon healthcare personnel to do everything they can to prolong life and leave the rest up to God (Braun et al., 2008).

The continued reliance on God's plan during decision making at the end of life is evident in one study which showed that 47% of African Americans (*n* = 28), relied on God when making the decision to use hospice services (Noh & Schroepfer, 2015). The belief also exists that the endurance of pain and suffering associated with illness and death is a part of that plan; suffering is seen by some as a part of the reality of life and is necessary to be Christ-like, “we have to suffer just like Christ suffered” (Yancu et al., 2015, p. 384). Others stated that the suffering can be tolerated because God does not give more than one can manage (Braun et al., 2008).

Associated with the belief in God’s presence and control in one’s life are the rituals used to communicate with and acknowledge God’s presence, particularly at the end of life. Pullis (2011) examined the perceptions of hospice care among African Americans and found that religion was a common theme among end of life rituals. Participants in the Pulllis study believed that religious rituals should be supported by hospice caregivers. These participants stated that hospice allowed time to take care of any unfinished business with God prior to death (Pullis, 2011). However, Taxis (2006) found that participants were concerned that African American religious practices would not be embraced in the hospice setting. The belief was that hospice workers are primarily Caucasian and hence will not embrace African American religious traditions at the end of life. Participants stated that the hymns sung and the preaching in African American churches were important even in the dying process, “I don’t want to die in a place where the spirit isn’t there. It’s important to be in a place where your traditions are embraced, not tolerated” (Taxis, 2006, p. 82). However, Noh and Schroepfer (2015) reported results contrary to this belief; they found that 59% of participants indicated that choosing hospice allowed them to practice their spiritual and religious rituals. Noh and Schroeper also reported that 41% of participants stated that healthcare personnel including hospice personnel are provided by God to care for others; participants even stated that hospice care was sent from God for those who need the service.

The premise of hospice care based on comfort and not curative care may be seen by some African Americans as conflicting with their religious beliefs. However, varying beliefs within this community must also be considered. Nevertheless, religious beliefs seem to be one of the major considerations in the decision to use hospice services and need to be better understood. These varying religious beliefs can formulate a framework for treatment decisions, including the use of hospice care services (Johnson et al., 2005).

Mistrust of the Healthcare System in African American Decision Making About Hospice

African American mistrust of the healthcare system is well documented in the literature as an influencing factor at the end of life (Bullock, 2011; Ludke & Smucker, 2007; Torke et al., 2005; Wicher & Meeker, 2012). For some African Americans, the Tuskegee syphilis study is stated as one of the reasons for their mistrust and is seen as a symbol of mistreatment by a traditional American system (Kennedy, Mathis, & Woods, 2007). Many hospice patients are typically older persons (NHPCO, 2015) who were alive during the time of the Tuskegee study and therefore may be familiar with the study, and believe that African Americans are still likely to be treated as guinea pigs by the healthcare system (Cort, 2004; Kennedy et al., 2007). Participants in the Pullis (2011) study clearly reported that they did not trust doctors because of their memory of Tuskegee. This older group of potential hospice users, given their historical experiences, may hold the belief that their race is devalued in the eyes of American society, and do not trust healthcare providers to tell the truth. If a Caucasian provider suggested hospice, participants in another study agreed, “Oh, you’re trying to get her out of here…you’re trying to get rid of her” (Taxis, 2006, p. 82). For participants of the Taxis study, it appeared that the suggestion of hospice was viewed as a method used by Caucasian healthcare providers to get rid of African American patients by allowing them to die.

In an examination of racial differences in the willingness to use hospice services, Ludke and Smucker (2007) found that Blacks who mistrusted their physicians were less likely to consider hospice use in the future even if they had previous exposure to hospice care. However, in the same study, 49% of Blacks (n = 220) who were satisfied with their care, even though they mistrusted their physicians, were likely to consider future hospice use compared to 13% who were not satisfied with their care (Ludke & Smucker, 2007). The significant interaction among race, exposure to hospice, and physician trust indicated that both physician trust and exposure need to be explored whenever one is discussing making decisions about using hospice. While Ludke and Smucker's study used a large random sample using a computer-aided telephone survey, many of the questions were dichotomous responses.

Another facet of African American mistrust of the healthcare system is the race of those providing care, particularly at the end of life. The perception of participants in the Taxis (2006) study was that hospice services were staffed predominantly by Whites, who could not be trusted to provide adequate care for or to respect the traditions of an African American patient. Of note in Taxis' study, was that participants who were African American healthcare providers stated that they were easily accepted into the homes of patients; these participants attributed this to being of the same race as the patients.

African American mistrust of the healthcare system particularly at the end of life is well documented in the literature. In a comprehensive review of the literature on factors that influence African American end of life preferences, Wicher and Meeker (2012) found that mistrust was a common factor of influence in hospice decision making.

Given the historical legacy of unequal treatment and the current disparities in healthcare, the idea of palliative and hospice care, which is in part the withdrawal of curative treatment at the end of life, may cause some African Americans to question if they are being told the truth about their prognosis and if they are getting the care needed. The current study highlighted how the various aspects of African American mistrust, fit into the decision-making process of hospice use among African American family caregivers.

Knowledge of Hospice Services in African American Decision Making

There is a lack of knowledge of the basic tenets of hospice or the services provided among the African American population (Johnson, 2013; Johnson et al., 2008; Rhodes, Teno, & Welch, 2006; Taxis, 2006). Pullis (2011) found that participants were unaware of services offered, cost issues surrounding hospice, and eligibility requirements. Johnson et al. (2008) found that the number of African American participants who had never heard of hospice was four times greater than the number of their Caucasian counterparts. Participants were unfamiliar with the term *palliative care* and did not know what hospice meant.

In addition to the lack of knowledge, negative or erroneous knowledge can also affect decision making. While discussing their knowledge about hospice, Yancu et al. (2015) reported one African American participant who stated, “It’s the last stop…they kill people out there. You go in, you’re not coming out” (p. 384). Others associated hospice use with giving up or hopelessness (Yancu et al., 2015; Zhang, Zyzanski, & Siminoff, 2012), and a place where the care is substandard and patients are left alone to die (Taxis, 2006; Yancu et al., 2015). Noh and Schroepfer (2015) reported the misconception that hospice meant going to a hospital and not being able to remain at home as long as possible. Bullock (2011) summed up African American participants' beliefs about hospice care as giving up versus White participants' beliefs as symptom management and comfort care. The decision to use hospice services when presented as an option would be difficult, when there is limited or no awareness or erroneous information of the service (Johnson et al., 2008).

Family Involvement in African American Hospice Decision Making

Family plays an integral part of many life altering decisions for African Americans (Campbell et al., 2010; Mazanec et al., 2010). African American family caregivers are involved in decisions related to finances, coordination of care, treatment, and end of life decisions like the discontinuation of life sustaining treatment (Conner & Chase, 2014). Hospice care at the end of life was considered a feasible option for patients when family members and loved ones agreed (Yancu et al., 2015). Noh and Schroepfer (2015) found that 61% of respondents exploring hospice access and use by terminally ill elderly African American patients, reported the involvement of family in their decision to use hospice services. Often near the end of life with a chronic illness, these family members or significant others are in the role of informal primary caregiver and possible decision maker (Braun et al., 2008; Campbell et al., 2010; Huang et al., 2012). As patients' conditions progress, family caregivers may serve as primary decision makers and may sometimes have legal designation as decision makers (Braun et al., 2008; Huang et al., 2012). It is important to note that for African Americans, family may not just be limited to blood relatives, but may include those named as relatives but have no blood relation, clergy, and members of a church community (Campbell et al., 2010). African American participants reported dissatisfaction when spiritual and community leaders were not allowed to participate in the care of loved ones receiving hospice services (Bullock, 2011).

Based on the evidence, family members may need to be included when hospice is introduced to African American patients and research about decision making needs to include the perspectives of all family members. One aspect about families' involvement that was not noted in the literature reviewed, was any discussion of family conflict when making the decisions. The review of quantitative studies did find measures of family conflict and qualitative studies did not describe questions regarding possible conflict. Although family has been identified as important, how the family may facilitate or hinder the decision-making process is not fully understood. African American hospice decision making is influenced by various factors. It is important to note that these factors do not exist in isolation and the decision-making process to use or not use palliative and hospice services are a result of a combination of factors, beliefs, and values (Johnson et al., 2008).

Decision-Making Theories Explaining African American Use of Palliative/Hospice Care

Most of the literature reviewed by the researcher on the decision making surrounding hospice and palliative care use in African Americans was atheoretical. Only three studies used decision-making theories to guide the designs (Conner, 2012; Conner & Chase, 2014; Noh & Schroepfer, 2015). The frameworks used in the three studies were based on Andersen's (1968, 1995) behavioral model of health services use.

In the first study, Conner (2012) used demographics, beliefs and values, spirituality, social structure, and social relationship, all variables from Andersen's model, and tested their significance as predictors of hospice use among Blacks. Conner (2012) found that the predisposing characteristics of demographics and social structure and the enabling characteristic of social relationships were significant in the prediction of hospice use by Blacks.

Noh and Schroepfer (2015) used the behavioral model for vulnerable populations, a version of Anderson’s original model, to guide a study exploring the structural barriers terminally ill African American elders face when accessing hospice, and the reasons they chose to use hospice. Noh and Schroepfer found that the initial structural barriers from the vulnerable populations model of income, lack of insurance, location of the hospice agency, and administrative procedures did not preclude hospice use. However, religion, family-centered culture of care, and information sources were significant factors in the participants’ reasons for choosing hospice (Noh & Schroepfer, 2015).

Lastly, Conner and Chase (2014) used Andersen’s model to examine end of life caregiving and decision making among Blacks from the informal caregiver’s perspective. Conner and Chase found that family involvement, beliefs and values, and the process of medical care were significant factors in the decision to use health services among Blacks. In these three studies, Andersen’s model was supported either partially or completely.

The lack of use of theoretical frameworks or the uncovering of theoretical frameworks in the exploration of African American hospice decision making, is a gap in the literature that highlighted the need for the current study. Noh and Schroepfer (2015) suggested that future research explore the experiences of family caregivers of older African American caregivers in their use of hospice care. Furthermore, Noh and Schroepfer suggested the use of an inductive research approach like grounded theory, to improve the knowledge of African American decision making and experiences surrounding hospice use for their loved ones. Conner (2012) also suggested that further research examine the role of the informal caregiver and their influence on health services use like the use of hospice care. These suggestions for future research supported the need for the current study.

Summary

This review of the literature provided insight into the common factors that influence African Americans' decision making surrounding general healthcare needs and hospice care. Similar influencing factors were observed for general healthcare and hospice care decision making. African Americans value family-centered decision making versus individual decision making during times of illness and at the end of life (Campbell et al., 2010, Johnson, 2008; Schubart et al., 2015). Mistrust of the healthcare system and healthcare providers is a historic factor that continues to affect the choice of treatment and care at all stages of illness and dying (Peek et al., 2013; Waite, 2008). Cultural beliefs and values such as the beliefs surrounding the importance of religion and God in treatment and end of life care situations were also common (Braun et al., 2008; Campbell & Ash, 2007; Torke et al., 2005). One difference in the decision-making factors at times of illness versus end of life, was that physician-patient communication was a common influence in general decision making, while knowledge was a common influencing factor in hospice decision making. However, these two factors may be encompassed within the cultural mistrust that African Americans have for healthcare providers that is common during both illness and hospice decision making.

Family-centered care, mistrust, knowledge, communication, and cultural and religious beliefs may help to explain what influences the decision-making process; however, what was unclear in the literature was the actual process and the role of these factors when African Americans make healthcare decisions during illness and for hospice use. Evident in this review was the lack of decision making models or theoretical frameworks to explore healthcare and hospice decision making among African Americans. Only five studies referenced decision-making models used to frame portions of the study design; however, none of these studies used or produced a model that explained the African American healthcare or hospice decision-making process.

Theoretical Model

Andersen’s behavioral model for vulnerable populations was the theoretical model that informed the approach to this study. In the 1960s, Andersen developed the original behavioral model for health services use (Andersen, 1968, 1995). The original model has since undergone several revisions and expansions, one of which is the behavioral model for vulnerable populations (Gelberg et al., 2000). The model was originally developed to gain a better understanding of why families use health services, to define and measure equitable access to healthcare, and to assist in developing policies to promote equitable access to healthcare (Andersen, 1968, 1995).

In later years, there was a need to include the factors that make populations vulnerable and influence their use of health services; hence, the behavioral model for vulnerable populations (Gelberg et al., 2000). Andersen’s original, expanded, and revised models specific to vulnerable populations informed the current study, which had a larger purpose to devise strategies to improve the equitability of hospice service use by African Americans.

The behavioral model for vulnerable populations consists of three overarching concepts: (a) population characteristics, (b) health behavior, and (c) outcomes.

Population characteristics include predisposing, enabling, and need factors (Gelberg et al., 2000). Each of these concepts can further be divided into traditional and vulnerable domains, encompassing concepts such as demographics, social structure, health beliefs, personal/family resources, community resources, perceived health, personal health practices, use of health services, health status, and satisfaction with care (Gelberg et al., 2000). Andersen (1995) posited that each of these concepts affects the other in the individual or family's decision to use healthcare services and their experience with healthcare services. Figure 3 contains a visual representation of the model.

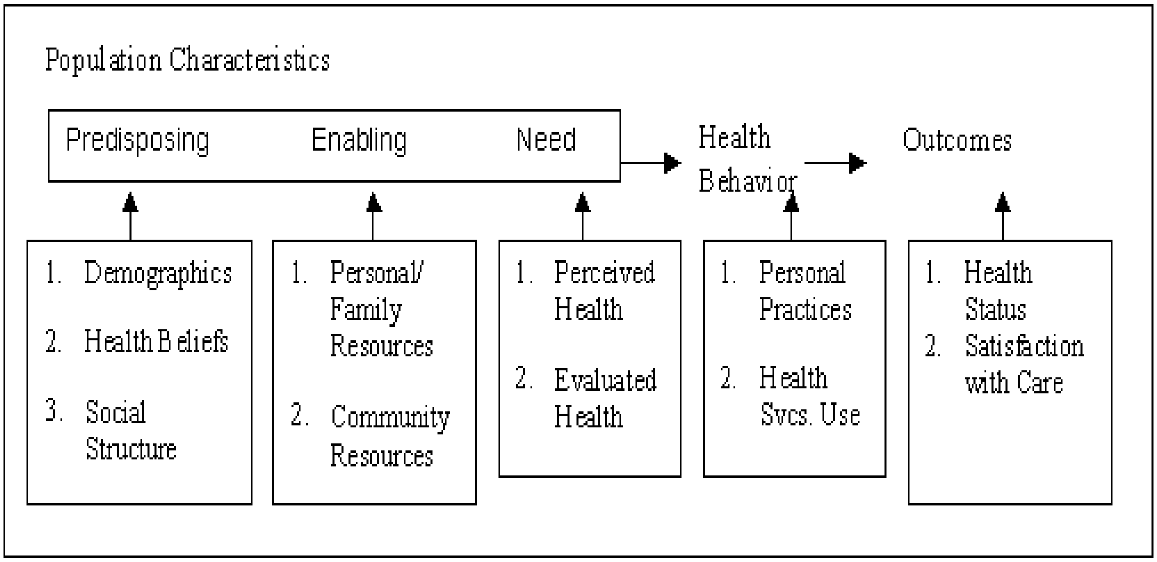


Figure 3. The behavioral model for vulnerable populations. Adapted from L.Gelberg, R. M. Andersen, & B. D. Leake, 2000, The Behavioral Model for Vulnerable Populations: Application to Medical Care Use and Outcomes for Homeless People. *Health Services Research, 34*(6), p. 1278.

Andersen's original model has been used to explain and describe health services use in various vulnerable populations both during illness and at the end of life. In the current study, Andersen's model for vulnerable populations was used as a starting point to examine variables defined in the literature suggesting reasons why African Americans might decide to use hospice. Specifically, elements of the model were used to inform the initial interview questions.

In contrast to well-defined and documented barriers to AA hospice use, the current study used a grounded theory approach because there was limited data regarding the decision-making process of those African Americans who did choose to use hospice services. The main goal was that once there was a better understanding of this process, future intervention could be developed that would capitalize on this information. Therefore, although grounded theory is an inductive method that results in theory generation (Corbin & Strauss, 2015), relevant major concepts of theoretical frameworks can still be applied loosely to provide a starting point in developing the study (K. Charmaz, personal communication, July 29, 2016). In keeping with the grounded theory methodology, the process of theoretical sampling was used to assist in developing subsequent questions based on the participants' reported experiences (Mitchell, 2014). Theoretical sampling allows the researcher to ask additional questions about new concepts that may become known during interviews; questions that are not included in the original interview guide (Charmaz, 2014).

The major concepts of Andersen's vulnerable populations model applied to this study are those related to the predisposing, enabling, and need characteristics of the population, and health status and satisfaction with care outcomes. Table 1 contains an illustration of how these concepts informed initial interview questions. A complete list of interview questions and probes are located in Appendix C.

Summary

This literature review provided a background for the current study and identified the gaps in the literature that justified the need for the study—the lack of understanding of the process of decision making of African Americans families when choosing to use

Table 1

Examples of Interview Questions and Corresponding Theoretical Concepts

Questions	Theoretical concept
Please tell me about the decision to use hospice services for your loved one.	Population characteristics (predisposing, enabling, and need factors)
Other than people, tell me about other considerations that influenced the decision to use hospice.	Population characteristics (predisposing, enabling, and need factors)
Tell me about the discussion you had with other family members, if any, about the decision to use hospice.	Population characteristics (enabling and need factors)
Please tell me about your experiences with hospice services.	Outcomes

hospice services. Gaining an understanding of this process can help to improve the decision-making process for African American families at the end of life. A theoretical framework guided the interview questions used in the grounded theory interviews, to explicate more fully a theory of the decision-making process used by African American family caregivers to choose hospice for their seriously ill family member.

CHAPTER 3

METHODS

Use of hospice services at the end of life involves a complex combination of factors that influence the decision-making process for patients and families. Because little is known about the decision-making process of African American family caregivers who use hospice services for a loved one, and to explore their decision-making process, a qualitative grounded theory methodology was chosen. This chapter contains a description of the sample, the recruitment process, strategies to ensure rigor, and the protection of human subjects involved in the study.

Purpose of the Study

The purpose of the qualitative study was to understand the African American decision-making process to use hospice care services from the perspective of the family caregiver. The study was conducted in the southeastern United States.

Research Questions

A central research question and five subquestions guided this study:

What is the decision-making process for African American family caregivers to use hospice service for their loved one?

1. What is at the core of African American family caregivers' decision-making process to use hospice services for a loved one?

2. What factors assist or impede African American family caregivers in their decision to use hospice services for a loved one?
3. What resources do African American family caregivers employ in their decision to use hospice services?
4. What is the role of the African American family caregiver in the decision-making process to use hospice services?
5. What is the theoretical model that explains the decision-making process of African American family caregivers' decision to use hospice services for their loved one?

Qualitative Research Approach and Design

A qualitative research methodology was chosen for this study because it allowed the exploration of an area that has not been thoroughly researched—the phenomenon of African American families' decision to use hospice services. Qualitative researchers study phenomena in their natural settings, with the goals of describing, understanding, interpreting, or ascribing meanings to the phenomenon being studied (Denzin & Lincoln, 2000). Creswell (2013) described five approaches a qualitative researcher can take to achieve their goals: (a) narrative, (b) phenomenological, (c) grounded theory, (d) ethnographic, and (e) case study. Each approach addresses different aspects of people's experiences with a phenomenon, and has specific steps guiding data collection and analysis. To address the purpose of this study, which seeks to understand a phenomenon of which little is known, a grounded theory approach was used. This approach was selected because of the nature of the central research question, which sought to explain the process of decision making that African American family caregivers use when deciding to use hospice services for their loved ones. Grounded theory goes beyond describing a phenomenon; it is designed to uncover theory from collected data (Glaser & Strauss, 1967). Grounded theory enables the researcher to develop a substantive theory that can be useful in explaining and predicting behaviors, and provide a perspective on those behaviors (Glaser & Strauss, 1967). Grounded theory also provides a systematic approach that allows for a continuous interplay between data collection and analysis, which leads to the development of a substantive theory about a phenomenon of interest (Corbin & Strauss, 1990). Employing a grounded theory approach provided a perspective and an understanding of the behaviors involved with African American caregivers' decision-making process to use hospice services for their loved ones, and resulted in a substantive theory that explains the process.

Grounded Theory Overview

Grounded theory was first introduced by sociologists Glaser and Strauss. Glaser and Strauss (1967) posited that grounded theory provides a mechanism for generating theory grounded in the gathered data instead of based on previous assumptions. The grounded theory methodology subsequently underwent revisions resulting in three well-known iterations.

The initial version of grounded theory, as put forth by Glaser and Strauss, was based on a positivistic paradigm, which purports that knowledge can be verified through scientific procedures and that the researcher can maintain a distance and independence from the data (Charmaz, 2000; Lincoln & Guba, 1985). Glaser and Strauss later parted ways and Strauss collaborated with Corbin on a version of grounded theory that had some positivistic tenets (Charmaz, 2000), and the underpinnings of pragmatism and symbolic interactionism (Corbin & Strauss, 1990). Important principles gleaned from both pragmatism and symbolic interactionism suggest that individuals control what happens to them through responses to their environment, and can make choices based on their perception of the options in that environment (Corbin & Strauss, 1990). These principles are based on the premise that phenomena are continually changing in relation to the environment. Grounded theory seeks to reveal the environment, and explain how individuals respond to their environments and the outcomes of their responses (Corbin & Strauss, 1990).

The third version of grounded theory embodies a constructivist view that emphasizes the phenomenon being explored as opposed to the methods being used to study that phenomenon (Charmaz, 2000). Charmaz also posited that the researcher comes to the research arena with an interpretive frame of reference based on prior experiences and interests, and contributes to the construction of data.

To achieve the purpose of this study, the approach developed by Corbin and Strauss (1990) was used. While similar to the initial approach put forth by Glaser, Corbin and Strauss' version is a more systematic approach that provided specific steps to guide the process. These steps involve the constant comparison of data to developing categories and the saturation of those categories, the axial coding phase that involves the identification of a core phenomenon and its related conditions, and selective coding where the theory or model is developed (Corbin & Strauss, 2015; Creswell, 2013). For any researcher, particularly this novice researcher, using these specific steps provided a reliable method of theory construction from the data (Corbin & Strauss 2015). Use of Corbin and Strauss' delineated procedures in this study, provided the basis for future studies using quantitative methods. In addition, this study revealed and explained the environment in which African American caregivers make decisions regarding hospice care for their loved ones. The study also explained the responses of African American caregivers to their environment and the use of the perceived options available to them in their decision-making process. Other methods can provide a similar explanation; however, the very specific structure of this approach sets it apart in its explanation of the phenomenon of African American caregivers' decision to use hospice services.

Philosophical Assumptions

Philosophical assumptions are the values, beliefs, ideas, and perspectives upon which researchers base their work (Munhall, 2012). These assumptions influence the formulation and execution of the entire study (Denzin & Lincoln, 2000). Creswell (2013) delineated four philosophical assumptions underlying qualitative research: (a) ontological, (b) epistemological, (c) axiological, and (d) methodological.

Ontology

An ontological assumption asks the question, "What is reality?" and assumes reality is seen from various viewpoints (Creswell, 2013). In a qualitative study, this is illustrated through the themes discerned from the various participants' perspectives (Denzin & Lincoln, 2000). During data analysis, the principal investigator (PI) remained vigilant in addressing personal views about the data, so not to affect the interpretations of the participants' realities.

Epistemology

Epistemology asks the questions, “What is knowledge?” and “How do we know?” The researcher attempts to get as close as possible to that which is being researched and considers the participants’ experiences as valid knowledge (Creswell, 2013). This concept is illustrated by direct quotes from participants, obtained through the researcher’s insider status; thus allowing knowledge to be obtained from the direct subjective experiences of the participants (Creswell, 2013). The structure of the study was such that the PI was the only data collector. This afforded the PI the opportunity to establish rapport and trust with participants; thereby, achieving the insider status that is necessary. Interviews were offered as either face-to-face interviews or telephone interviews and conducted in the manner preferred by the participants. This allowed the interviews to be carried out in an environment that was comfortable for the participants.

Axiology

The axiological assumption states that research is heavily influenced by values and biases from both the participants and the researcher (Denzin & Lincoln, 2000). The unique aspect of qualitative research is that the researcher acknowledges and discusses these values and biases and their impact on the interpretations of the findings (Creswell, 2013). The PI used the structured and rigorous approach of grounded theory to capture participants’ views. Self-reflection and journaling were used to identify biases and behaviors that the PI brought to the data and the potential influences of these biases and behaviors on the study process and outcomes (Corbin & Strauss, 2015).

Methodology

Methodology refers to the process and language of research (Creswell, 2013). Qualitative researchers use a logical inductive method that examines the specific details of the data within the context of the study before any generalizations are made (Creswell 2013). The inductive method of data analysis includes interplay between the data and the researcher, while taking into account the beliefs and values brought by that researcher (Corbin & Strauss, 2015; Creswell, 2013). The systematic approach specified by Corbin and Strauss (2015) was used to achieve the necessary inductive logic. To manage effectively the interplay between data and researcher, the PI consistently examined personal biases during data collection and analysis. During periods of self-reflection, the PI referred back to the purpose of the study and, based on the data and observations, revised the interview questions to reflect the study purpose better.

Sampling

Purposeful sampling is used in qualitative research to allow the researcher to choose participants who will purposefully provide an understanding of the phenomenon being studied (Creswell, 2013). In this study, theoretical sampling, a form of purposeful sampling was used. Theoretical sampling is a central tenet of grounded theory where the researcher simultaneously collects, codes, and analyzes data in order to decide what data to collect next (Coyne, 1997; Glaser, 1978). Participants are selected based on the needs of the developing categories and emerging theory (Coyne, 1997). Theoretical sampling dictates that sampling continue based on the concepts that emerge through constant comparison of data gathered to the emerging categories, until saturation is achieved (Corbin & Strauss, 1990; Creswell, 2013). With grounded theory, saturation is measured by a constant comparison of data to find emerging categories (Creswell, 2013); saturation is met when no new concepts emerge from the data (Corbin & Strauss, 1990; Woods, Gapp, & King, 2016) and the researcher can substantiate the theory (Charmaz, 2014).

Sites and Sample

Participants were recruited from the southeastern United States. Eligibility criteria included (a) self-identification as African American; (b) age 18 years and older; (c) had within the last year or currently had a family member in hospice care; (d) self-identification as an informal caregiver (any unpaid relative, partner, or friend) who was involved in the care and decision making of the care recipient; (e) could speak, understand, and write English; and (f) had no cognitive impairments. Exclusion criteria included caregivers who were within the age criteria and identified as African American but had a family member in hospice more than one year prior to the study or received payment for their services as the caregiver.

Fliers describing the study were distributed at two African American churches in the Atlanta metropolitan area. Formal approval to recruit participants from the churches was obtained in writing from church clergy. Fliers were also distributed to the Atlanta chapter of Chi Eta Phi Nursing Sorority Incorporated, the Birmingham chapter of the National Black Nurses Association, and at two health fairs in the Atlanta, Georgia area. Interested participants were requested to contact the PI. The fliers included the PI’s contact information so potential participants could review the information at their convenience and contact the PI if they were interested in learning more about the study. Individuals interested in the study contacted the PI, were explained study procedures, and screened for study eligibility. Participants who met the eligibility criteria were enrolled in the study. The sample obtained was heterogeneous in areas of familial relationship to the patients, and represented a wide range of ages; therefore, no specific attempts were made to add further variation based on demographics. Participants received a $25 gift card for taking part in the study.

Data Collection

Qualitative researchers gather rich data through various methods including formal interviews, observations, conversations, public records, and the researcher's own reflections (Denzin & Lincoln, 2000). To obtain the necessary rich data of the individual experience with the decision-making process, individual in-depth interviews were used. The interviews allowed the PI to gather the pertinent details necessary to understand the phenomenon (i.e., the decision-making process of African American family caregivers who use hospice for their loved one), and uncover a theory to explain the process.

Prior to each interview informed consent was obtained. Collection of demographic data occurred at the beginning of each interview using the demographic information form (Appendix D). A semistructured interview guide was used to facilitate the interviews (Appendix C). Interview questions were developed based on concepts of Andersen's behavioral model of health services use for vulnerable populations and generally reflected the concepts of predisposing characteristics, enabling, need, and outcome factors (Gelberg et al., 2000). Probes were used to explore further information about the decision-making process. The interview guide was reviewed by experts in the fields of caregiving, qualitative research, and palliative care decision making for appropriateness of questions and to ensure that the necessary aspects of African

American hospice decision making were addressed. Interviews averaged about 60 minutes, were audiotaped, and transcribed verbatim.

Field notes were used to reflect information about the interview process and/or the participants. Memoing was used to capture the PI’s ideas and decisions from the first coding session to the end of the research process. It was important to document these ideas and decisions because they framed the process as perceived by the PI. This is integral to grounded theory (Corbin & Strauss, 1990).

Data Analysis

Data analysis in grounded theory begins at the outset of the study because it directs and drives the next set of interviews (Corbin & Strauss, 1990). Grounded theory analysis is systematic and detailed, and all steps must be followed to ensure the rigor and efficacy of the approach. Raw data reported by participants or observed by the researcher are analyzed to create concepts that are the basic units of analysis of a grounded theory study. The concepts that emerge are then grouped to formulate categories; these categories then become the foundation of the developing theory (Corbin & Strauss, 1990).

The process of analyzing the data was conducted in three phases: open coding, axial coding, and selective coding (Corbin & Strauss, 1990). Open coding was the first step following collection of the initial data. It is the beginning process of formulating concepts and categories, with the goal that new insights about the phenomena would be uncovered from the data (Corbin & Strauss, 1990). During open coding, occurrences in the data were compared in order to identify similarities and differences, which were then labeled as concepts; similar concepts were grouped together to create categories. The data were continually reviewed and categorized through the process of constant comparison. Open coding identified the initial elements of the caregiver's hospice decision-making process and provided ideas about that process that were pursued in further data collection. As data collection continued, elements of the decision-making process that supported similar concepts and had similar properties or subcategories were grouped together to create additional categories. Further analysis was conducted to identify the dimensions of each subcategory. Dimensions show the range of each of the properties (Creswell, 2013).

The next phase of analysis was axial coding, in which the core phenomenon was identified. The core phenomenon is the major theme that emerged from the open coding phase (Creswell, 2013). The researcher referred back to the data in order to create categories around the core phenomenon; the resultant model is the axial coding paradigm. The core phenomenon is the major theme of the study. The core phenomenon is the category that appears frequently enough in the data that it encompasses all the participants of the study (Corbin & Strauss, 2015). The categories created around the core phenomenon come from the data and are all linked to the core phenomenon. They can be identified, according to Corbin and Strauss (2015), as causal conditions, strategies, intervening conditions, and consequences. Causal conditions are factors that caused the core phenomenon, strategies are measures taken in reaction to the core phenomenon, intervening conditions are situational factors that affect the strategies, and consequences are the result of using the strategies (Corbin & Strauss, 1990).

The final step in the coding process was selective coding. It was in this stage of coding that the model to explain the decision-making process of African American caregivers in their use of hospice services for their loved ones was created. During the selective coding phase, a conditional matrix was created to assist in understanding how micro factors (e.g., personal or individual factors) involved with African American caregivers' decision-making process, interact with macro factors (e.g., social or historical factors) to influence the decision-making process. Based on the model created, propositions or hypotheses are developed to describe the interrelationship of the categories (Corbin & Strauss, 1990).

Rigor

Establishing rigor in grounded theory involves evaluating the adequacy of both the techniques used in the study and the theory produced (Cooney, 2011). Glaser and Strauss (1967) described the idea of rigor in a grounded theory study as the credibility and fittingness or applicability of the study. The theory produced must be practically applicable to the area to which it is being applied (Glaser & Strauss, 1967). Credibility refers to the believability or plausibility of the derived theory, and fittingness or applicability refers to whether the theory applies to the situation it is attempting to explain (Glaser & Strauss, 1967).

To enhance rigor, Chiovitti and Piran (2003) delineated three standards of rigor: credibility, auditability, and fittingness as suggested by Glaser and Strauss (1967). Chiovitti and Piran further specified eight methods for research practice associated with these standards that should be incorporated into a grounded theory study (Table 2). The research practices specified in Table 2 were used to enhance study rigor.

To ensure credibility, theoretical sampling and constant comparison were used to allow participants to guide the inquiry (Chiovitti & Piran, 2003). Theoretical sampling was achieved by using the inclusion criteria and sampling based on the concepts that began to emerge during initial data analysis (Corbin & Strauss, 2015). Constant comparison was used throughout the data analysis process. This was important as it enabled the PI to evaluate the emerging theory against participants' perceptions and emotions related to the phenomenon. Reflective journaling and debriefing meetings with field experts were used to help articulate the PI's views and insights and to identify emerging concepts (Chiovitti & Piran, 2003; Corbin & Strauss, 2015).

Table 2

Standards of Rigor and Methods of Practice

Standards of rigor	Suggested methods of research practice
Credibility	1. Let participants guide the inquiry process using theoretical sampling and constant comparison
	2. Check the emerging theory against participants' meanings of the phenomenon
	3. Use participants' actual words in the theory
	4. State the researcher's personal views and insights about the phenomenon explored by means of: a) Reflective journaling b) Debriefing
Auditability	5. Detailed descriptions of the research process
	6. Specify the method of participant selection
Fittingness	7. Describe the scope of the research in terms of the sample, setting, and the level of the theory generated
	8. Describe how the literature relates to each category which emerged in the theory

Note. Adapted from "Rigour and Grounded Theory Research," by R. F. Chiovitti & N. Piran, 2003, *Journal of Advanced Nursing, 44*(4), 427–435.

Auditability was enhanced using audit trails in which the PI documented detailed descriptions of the research process and decisions (Cooney, 2011). Specific to the grounded theory approach, audit trails were captured in memos that gave insight into the study's design, data collection, sampling, and analysis (Cooney, 2011). Together these strategies help others to understand the PI's rationale behind methodological decisions made; thereby, increasing study auditability (Chiviotti & Piran 2003; Cooney, 2011).

Fittingness, also referred to as applicability by Glaser and Strauss (1967), is enhanced through theoretical sampling and clear descriptions of the reasons and process involved in sampling (Cooney, 2011). Readers of the study must have an adequate amount of detail about the sample to decide if it is representative of the problem being studied (Cooney, 2011). In order to enhance fittingness, a clear description of the study context has been documented and the relationship between the emerged categories and current literature has been chronicled. Both strategies assist in evaluating study applicability (Chiovitti & Piran, 2003).

Protection of Human Subjects

The study of African Americans' decision-making process in choosing hospice care services involved ethical issues of vulnerability, confidentiality, and harm. Vulnerable populations are individuals who have been harmed and exploited in research (Shamoo & Resnik, 2009). The history of the Tuskegee syphilis study can render African Americans vulnerable simply based on this definition; however, the U.S. federal guidelines on vulnerable populations do not list African Americans as a vulnerable population. The guidelines do list the economically and educationally disadvantaged (U.S. Department of Health and Human Services, 2010), which can encompass many African Americans.

Potential Risks

Given the historical legacy of mistrust of research within the African American community, issues of confidentiality are also heightened. Vulnerability was also possible within this study population related to the sensitive and emotional nature of the topic of death or imminent death of a loved one, which could have resulted in emotional harm. Ethical considerations and human subjects' protection were therefore of utmost importance in the study. Potential risks also extended to the researcher, given the sensitive nature of the topic. The PI was at risk of compassion stress during the data collection and analysis phases of the study (Rager, 2005).

Strategies to Address Potential Risks

The University of Alabama at Birmingham Institutional Review Board (IRB) approved the study (See Appendix E). Subsequent to IRB approval, additional procedures to protect human subjects were to ensure that individuals were eligible to participate in the study and to obtain informed consent. To validate accuracy of consent further, a clear and accurate explanation of the study and the rights of research participants was provided throughout the study. Prior to data collection, informed consent was obtained by the PI using the consent form approved by the IRB. The consent form included (a) a description of all study procedures; (b) information regarding risks and benefits of participation; (c) a statement that participation was voluntary; (d) participants can refuse to answer any interview question; (e) participants can withdraw from the study at any time; (f) all responses will remain confidential; (g) interviews will be recorded with permission; (h) for participants whose family member is currently in hospice care, participation in the study is not related in any way to the medical care their family member receives; and (i) that a follow-up interview may be requested.

Specific strategies were used to address potential mistrust that the participants may have had regarding their participation. Use of researchers or interviewers of the same ethnicity as participants has been suggested as a method to address mistrust among African American study participants (Campbell, 2007; Kerkorian, Traube, & McKay, 2007). The PI self-identified as African American and conducted all interviews. Another strategy involved obtaining affirmative responses from participants during each interaction. Obtaining approval with each interaction gave participants an opportunity to continue or withdraw from the study at any time (Campbell, 2007).

Techniques were also used to preserve participant confidentiality. All potential identifying information was removed from interview transcripts and participants were asked to select their own identifying pseudonyms. The PI and the palliative care expert were the only persons to have access to participants' personal information. Audiotaped interviews were identified by the chosen pseudonyms, and along with the transcribed data, were stored in a locked file cabinet in a locked office. All paper copies of consent forms were kept in a separate locked file in the locked office. Only the PI had access to the office and file cabinets. Electronic data were stored on an encrypted, password-protected external hard drive. Due to the heightened concerns about confidentiality among African Americans, participants were reminded at the end of every contact how confidentiality was maintained (Campbell, 2007).

Participation in the study posed potential risk for psychological or emotional distress. The topic related to the death or imminent death of a family member is considered a sensitive topic. Participants were given time to answer questions at their own pace and periods of silence were honored. These strategies fostered an atmosphere of respect for their readiness to continue with the interviews (Elmir, Schmied, Jackson, & Wilkes, 2011). Participants could stop the interview at any time to prevent further emotional distress. When participants were notably distressed, they were asked if they wanted to continue the interview. In all cases, the participants elected to continue the interviews. Strategies to avoid harm to the PI included peer debriefing with the palliative care content expert, self-reflection, and journal writing.

Summary

The purpose of this qualitative study was to develop a model that explains the decision-making process of African American family caregivers to use hospice services for a loved one. A grounded theory approach was used. Data collection was achieved through individual, semistructured, telephone interviews. Data analysis procedures commonly used in grounded theory were used, including open coding, axial coding, and selective coding, with a resultant conceptual model of African American family caregivers' decision to use hospice services for their loved ones.

CHAPTER 4

FINDINGS

The findings of this study are organized by each level of the grounded theory analysis. The chapter begins with a description of the settings and participant characteristics, followed by the findings that emerged from open coding, axial coding, and the selective coding process that included a conditional matrix. The results of the analysis culminate with a description of the conceptual model that emerged from the study of African American caregivers' decision to use hospice care for a loved one.

Setting and Participant Characteristics

Caregivers (CGs) in this study resided in or used hospice services in Alabama, Florida, Georgia, and Louisiana. The proportion of African Americans in the population of these states ranged from 17% to 32%. Approximately 86% of these states' population has a high school or higher level of education, with about 26% at a college level. Median household incomes ranged from $45,000 to $51,000 (U.S. Census Bureau, 2017). As the state with most participants (82%), Georgia's general population, African American population, level of education, and household income were similar to the other states. In 2015, the proportion of Medicare decedents enrolled in hospice care at the time of death in these states ranged from 30% to 57%, with Georgia at 45%–50% (NHPCO, 2017).

Twenty African American CGs were screened for eligibility. Two did not meet the eligibility criteria, resulting in a sample of 18 participants. Table 3 contains pertinent

Table 3

Caregiver Characteristics (n = 18)

Characteristic	*M*	Range
Age	56	36–73
Days relative in hospice		
Deceased (*n* = 13)	48	0.125-180
Currently in hospice (*n* = 4)	43	7-90
	n	%
Gender		
Female	15	83
Male	3	17
Education		
College graduate	10	56
Some college	6	33
High school	2	11
Relative in hospice		
Mother	4	22
Husband	4	22
Sister	3	17
Grandmother	2	11
Father	1	6
Cousin	1	6
Friend	1	6
Niece	1	6
Primary patient diagnosis		
Cancer	8	44
Non-cancer	10	56
Stroke	3	17
Heart failure	1	6
Diabetes	1	6
Pneumonia	1	6
Multiple sclerosis	2	11
Brain tumor	1	6
Dementia	1	6

characteristics about the CGs in the study. CG participants ranged in age from 36 to 73 years with an average age of 56 years, were mostly female (83%), and college graduates or had some college education (89%). Fifty-five percent of the patients were female, with cancer being the leading diagnosis (44%). Four patients were receiving hospice services at the time of the interviews, while 13 were deceased. Patients' length of stay in hospice averaged 48 days for decedents and 43 for patients currently in hospice with a range of 3 hours to 6 months. Nine patients received inpatient hospice care and eight received home hospice. One patient initially spent time in an inpatient facility, but was then moved to home hospice one day prior to her death. The names used throughout discussion are pseudonyms created by the participants.

Open Coding

The process of review and analysis of interview transcripts initially yielded 12 categories: (a) hospice knowledge, (b) terminality of prognosis, (c) apprehension, (d) influencing factors, (e) emotions, (f) selection, (g) spirituality, (h) difficulty of decision; (i) hospice experience, (j) communication, (k) loved one's needs, and (l) expectations. Each of these 12 categories were further analyzed and assigned subcategories or properties and dimensions. These 12 categories were grouped into five major categories: (a) realizing the end of life, (b) hearing and believing, (c) shaping the decision, (d) selecting hospice service, and (e) experiencing hospice. Table 4 illustrates the five categories, subcategories, and their dimensions.

Realizing the End of Life

The first category reflects the CGs' understanding and acceptance of their family members' prognosis—their loved one was at the end of life (EOL). CGs' realization that their loved one would not get better and that death was near was integral to proceeding with the decision to use hospice care services. The two subcategories that emerged from this category were understanding that this is the EOL and accepting that their loved one was at EOL.

Table 4

Open Coding Diagram

Categories	Subcategories	Dimensions
Realizing the end of life	Understanding that this is the end of life	Clear understanding of patient prognosis Not sure of prognosis Reaction to and discussion surrounding EOL information
	Accepting that this is the end of life	Accepted the prognosis Did not accept the prognosis Facilitators of acceptance
Hearing and believing	Physician-CG communication	Perceived honesty communication Clarity of communication Effect on decision making
	Family-CG communication	Disagreements Consensus Effect on decision making
Shaping the decision	Feelings-CG	Types of emotions Influence on decision
	Taking care of their loved one	Physical care needs Loved ones wishes and how it was communicated Loved ones' comfort needs
	Knowing and learning about hospice	No knowledge Some knowledge Accurate knowledge Inaccurate knowledge Influence on decision
	Being leery about hospice	Sure; unsure Reason for uncertainty Influence
	The Lord has me	Influence of religious beliefs
Selecting a hospice service	Choosing a hospice agency	Choice of agency No choice of agency
	Deciding between coming home or going to a home	CG comfort with and ability to care for loved one at home Loved ones' wishes for home or inpatient facility
	Talking with hospice representatives	Perceived honesty of communication Clarity of communication
Experiencing hospice	Getting what they expected	Expectations met or not met Satisfied Dissatisfied Would they recommend to others

Understanding that this is the EOL. This subcategory describes the CGs' understanding of their loved ones' illness prognosis, lack of effective treatment options, and reaction to that information. For most of the CGs, the physician was the healthcare provider who introduced the terminality of their loved one's condition. The initial reaction to this information varied among the CGs. For most CGs, there was no confusion about understanding that their loved ones' condition would not improve and that they were at the EOL. However, for a few CGs there was confusion after speaking with the physician, since they did not recognize the extent of their loved ones' condition.

Mary spoke of the clarity of her understanding of her husband's condition. She reported that she could view the results of her husband's MRI scans, and the physician explained the scans as they related to the disease progression. She stated, "The doctor actually showed me his MRI and we knew, and I saw that, I knew he isn't coming out of this." Another CG, Mildred, also reported a clear understanding of her husband's EOL condition based on her physician's consistent communication. She explained, "Our pulmonary doctor throughout the surgeries said, 'Well, I'll keep him breathing as long as I can.' After the last time that's when they told us and we knew that." Mildred understood there was nothing else that could be done to reverse her husband's condition and that he was at EOL. Jake's understanding was based on discussions with his mother's physician during a previous illness. He explained, "When she walked away from that third stroke, they said if she had one more stroke that was going to take her out." Based on the physician's prior information, Jake understood that when his mother had a fourth stroke, she would not survive.

Four CGs reported some initial confusion after being told that their loved one was at the EOL. Sheryl described the confusion, “It’s confusion because she [patient] didn’t seem like she was failing to that extent.” Similarly, Sarah reported that she and her family were initially confused resulting in questions when the physician stated that her father was at EOL. She said, “Cause we had a bunch of questions, wasn’t just me, it was a lot of my family…what was involved with his care, his prognosis as well as his diagnosis.” Both CGs’ loved ones had chronic diagnoses that led to multiple hospitalizations over several years. Therefore, they both thought the current hospitalization was just another time their loved one would be treated and return home. However, they ultimately realized that this time was different.

Derrion reported knowing her cousin’s diagnosis but not realizing the extent of his illness. She explained, “You know, we didn’t think that he was there to get real sick and not ever come home…We thought that he just went to the hospital to be there, to be taken in, then he could come home.” Samantha also reported initial confusion, her mother had a brain tumor that in previous physician visits they were told was stable. She stated, “I was a bit confused because they told us before that the tumor was stable, so they didn’t have to do anything about it.” Samantha did not understand why a tumor that was stable was now causing her mother to be at the EOL.

For CGs who were initially confused, they did explain that their understanding was subsequently facilitated by further dialogue with the physicians and other healthcare personnel (HCP), and by watching the decline of their loved ones. Sarah reported meeting with her father’s care team to discuss her father’s condition further. She stated:

> We had a team meeting, I guess that’s what they call it, where my siblings, and my mom, and the doctor, the case worker, the charge nurse, and the nurses that

> were taking care of him, actually met…I honestly thought that they were all in agreeance, cause my dad was going down, he was going down pretty quick.

Speaking with these additional HCP and watching her father's decline facilitated Sarah and her family's understanding of her father's EOL condition.

The same was true for another participant, Samantha. She found that further dialogue with physicians, along with observing her mother's decline, helped her to understand her mother's prognosis. Samantha said, "I met with another group of doctors and talked some more…my mother wasn't responding anymore." More discussions with physicians and observing the change in her mother's condition helped her to understand that her mother was at EOL.

Understanding that a loved one was at the EOL was facilitated by HCP communication and in some cases witnessing their loved ones' declining condition. Observing their loved ones' physical decline was concrete evidence of the seriousness of their condition and helped them comprehend the situation. CGs' understanding that their loved ones were at the EOL was integral to the subsequent decision-making process to use hospice services. Evident also from the interviews was that a clear understanding that their loved one was at the EOL led most CGs to accept their loved ones' condition.

Accepting that this is the EOL. This subcategory described CGs' acceptance that their loved one was at the EOL. The data revealed that for the majority of CGs, understanding that their loved ones were at the EOL facilitated acceptance; however, there were also other contributing factors involved in the acceptance of their loved ones' condition. Those factors included the disease progression with the lack of further treatment options, witnessing their loved ones decline and the intensifying of symptoms, and not wanting their loved one to suffer.

Disease progression and the lack of further medical treatment options were explained by John, when he described the information given to them following his grandmother's surgery. He stated, "The tumors was spreading, they were going to spread rapidly and there was nothing that they can do in the hospital ICU [intensive care unit]." Mildred also described the progression of her husband's disease and the lack of further treatment options. She explained, "They would go in and laser down in that one area, but the cancer was impeding in both of the lungs. After a while so much scar tissue built up that they couldn't no longer do that." Jake also spoke of being told of a lack of treatment options resulting from his mother's disease progression. He stated, "They told us that there wasn't nothing they could do for us. They said the left side of her brain was gone, and blockages were coming up to catch the right side."

Sarah described that witnessing her father's decline facilitated her acceptance of his EOL prognosis:

> I guess just getting to that point where we had to accept that this is, you know, that was it, that's all, really not much more we can do…it was seeing him, being with him day in and day out, seeing that he wasn't getting any better, it was the way he was progressing, or declining, that really made us decide.

For Mary, her husband's intensifying pain was a factor in acceptance of his prognosis, along with his declining condition, "He was in increasing pain and I just didn't want him to suffer." Mary further described her acceptance:

> What is important is that the family understands, that they're not coming out of this, and that has to do with acceptance. Everyone is different when it comes to acceptance. But at some point, that acceptance becomes a reality because there's nothing else that doctors can do, and in my case, the doctors didn't just say that, they actually showed me, 'okay this is what's going on now'.

While most CGs accepted that their loved ones were at the EOL, three CGs did not describe accepting that their loved ones were at the EOL. Sonya explained that she knew her husband was dying but did not accept this reality. She said, “We, I mean, I probably did get he was dying but I didn’t want to see that.” Cecilia understood that her friend’s condition was terminal but also did not want to accept this fact. In her explanation of her initial understanding, she stated:

> She had a head scan at [the hospital] and the chart showed the cancer had spread, we found that it was the same cancer that had gone into the lungs. There were many nodes involved. So, they decided, and told us there, they said, ‘We’re not gonna be able to treat you, what we’re gonna do is buy time with palliative chemo.’

Cecilia understood the terminal prognosis but did not accept its reality; she was expecting life prolonging chemotherapy. Her friend’s worsening symptoms caused her to go to another healthcare facility, where the physicians deemed her too ill for chemotherapy, and suggested hospice care instead. Cecilia did not accept this explanation and believed that palliative chemotherapy was not done because of financial reasons. She stated, “My first impression was, well yeah you got Medicaid, so ain’t nobody gonna benefit from this…I personally think once she got into the private hospital, it had to do with billing, or coverage.” Cecelia believed that palliative chemo should have been done to prolong her friend’s life. She did not accept what she was told by the physicians; instead, she believed that their decision against life prolonging chemotherapy was related to her loved one’s type of insurance coverage. Though Cecelia never accepted her friend’s prognosis, she went along with her decision to accept hospice care.

The third CG, Antoinette, had in her possession a living will in which her husband stated that he did not want to be on life support. Antoinette did not agree with her husband’s wishes and stated, “So, to be truthful, I was just gonna have him be on life support for the rest of his days.” Antoinette did not accept that her husband was dying, and even though he was on life support, she wanted him to remain that way to prolong his life. She further stated, “I went ahead and held on to the paperwork [living will] for a week and then when the doctor called another family meeting…I went ahead and presented it to the doctor and his [the patient] family.” She further explained that she only presented the living will to honor her husband’s wish of peacefully transitioning. Thus, for this CG, the loved one had made the decision about EOL care.

Acceptance of their loved ones’ EOL condition for most of the CGs was an internal process that followed understanding, facilitated by their loved ones’ disease progression with lack of treatment options, and the intensifying of symptoms. For the three CGs who understood but never accepted their loved ones’ condition, this internal process never occurred. The majority of CGs realized that their loved ones were at the EOL. They understood and accepted their loved one’s prognosis. The realization was made of the finality of their loved one’s condition; they then acted on that realization and began the decision-making process of hospice use.

Hearing and Believing

This second category addresses the communication that emerged from the data and its effect on the decision-making process for the CGs. The subcategories that emerged address the communication between physicians and CGs and the communication between the CGs and family during the decision-making process.

Talking with the physician. Physician communication with CGs about their loved ones’ condition was integral to the realization that their loved one was at the EOL and to the hospice decision. For the majority of CGs, the physician was the one who introduced their loved ones’ EOL condition and the hospice option, these conversations occurred simultaneously. The data also showed that the relationship between the physician and

CG enhanced the communication. The majority of CGs reported satisfaction with physician communication. They described physician communication as being respectful, genuine, honest, and clear, and described the relationship as being comfortable.

Terri described the physician's respect for her intelligence during their discussions. She stated, "Being able to talk to the doctor on my level…having him understand, okay I'm not a doctor but I'm a smart person." This CG valued the physician's ability to speak to her in a way that she understood, while respecting her intelligence. Terri also explained why she believed that the physicians were genuine.

> I really felt like they were genuine when it came time to make that [hospice] decision, and to present us that [hospice] option, because they presented all the other options as well. I mean there were a whole bunch of procedures, I can't even remember the names, but there were a lot of things that they offered us, and then hospice was really the last thing that they offered to us. I really felt like that they were very genuine when they presented it [hospice] to us.

The choices presented to Terri were important in her perception of the genuineness of the physicians' communication. While being given other options for treatment was not the case for many CGs, being given choices in addition to the hospice option was important to Terri's positive view of the physician's communication and her decision making.

Physician honesty in communication was described by another CG, in addition to the level of comfort felt by the CG and her sister (the patient). She stated:

> We were comfortable with the doctor, she [the patient] was very comfortable with the oncologist…we all appreciated the doctor's manner…she [the physician] was very honest with us but she never said, 'you got so long to live' or something like that, but she told us very clearly that there was no cure for Stage 4.

This CG felt a level of comfort with the physician that seemed to enhance the communication and made it easier to accept the physician's assertion that her loved one was at the end of life.

The clarity of the physicians' explanation of hospice was described by another CG. She stated:

> I appreciated their help in preparing an extreme what will happen with hospice scenario, from the transfer from hospital, to hospice facility or to home, and saying that if there was any question or problem, they were always willing to assist me.

Clear physician communication occurred even when there were multiple physicians involved. Jaye reported, "They were very upfront with me…I talked to a different doctor every day, but they all went over exactly what, whatever was in the chart…no there were no differing opinions." Jaye's sister was in a teaching hospital. She therefore dealt with several different physicians and appreciated the consistency and clarity of the information she received.

Physician communication was important. The physician was often the member of the HCP who introduced the EOL condition of the patient and hospice as an option. The physicians' honesty, genuineness, clarity, and consistency of information in addition to the relationships they developed with the CGs, led to satisfaction with the communication and helped facilitate the decision-making process.

Talking with family. Family communication was important in understanding and accepting the patient's prognosis, and in the decision to use hospice. All CGs described discussions of the patients' condition and the hospice option with family members. The family members involved in most cases were members of the immediate family, like siblings, adult children, parents, and a spouse. Most CGs and their families attempted and reached consensus; however, some CGs described having the power to make the final decision regardless of consensus. A few even described initial disagreement with family members.

Sarah spoke of the consensus that was reached after a discussion that included her siblings and her mother, in making the hospice decision about her father. She stated:

> We had a family meeting after the [medical] team left…it was hard, it was hard to decide to go that [hospice] route. Just accepting, accepting the fact that this is where he was in his illness. And that we did everything, or did we, should we try anything invasive, should we try a feeding tube?...but eventually everybody got around the table and expressed how they felt, and we end up just, everybody just deciding, this [hospice] is the right thing to do.

Mildred described discussions and consensus amongst herself and her children, about her husband's condition. She stated, "Well, I have three adult children…so we're very close…the decision that was made was between me and our children."

Other CGs described some initial conflict in the decision making and spoke of the ability to make the decisions independently because of official power of attorney documents; however, they still had discussions with family members that led to a mutual decision. Jaye had the medical power of attorney for her sister and described some initial disagreement with her brother-in-law:

> In front of him [brother-in-law] I said to the doctor 'if she can't do it by herself she can't come home' and he [brother-in-law] said something about you know well she wants to come home, I said, 'yes, but they're only gonna provide a nurse during the day, that means when she wants to go to the bathroom at night, you're gonna have to get her up…it would be better for you if she was inpatient.' So, this was the conversation we were having to the side, but once we talked about it and the things he would have to do, he realized it was better for her to be inpatient…Even though she's married, I have the power of attorney over medical, so even if he said, 'I want outpatient,' I would've overrode him and said no, inpatient.

Precious described a similar situation, in which there was some initial conflict. Her brother accepted that their mother was at the end of life but she did not. She stated, "My brother kept talking about that there was nothing they could do for mom…you know how it is when two siblings disagree. To me, my brother was losing hope and I wasn't losing hope." Precious did not have an official power of attorney document but was the one making all the decisions for her mother. She further described that while she valued and welcomed her family's input, the decision was hers to make:

> Because I was the one to make it [decisions] all, what I said went, but I tried to respect them. Respect them and hear them out and stuff like that, but my name was on everything…When they [physicians] came back and said that the chemo didn't work, that's when I kind of was stuck…I got out of my selfish ways, and I listened to what my little brother was saying about hospice, 'It would be the best thing to make her comfortable'…my sister made me feel good she said, 'You've got to do what's best for her, not what's best for you.'

Both CGs had the ability to make independent decisions but still valued the input of their families in making the final decision.

Another CG also described discussions with her mother but also described communication with other family members in the form of information sharing, where consensus was not the goal of the communication. Terri explained her family communication this way:

> It was just me and my mom, because we had dual power of attorney, but my mom is really leaving it all up to me basically…even though there's other grandchildren and other family members around…so my mom and I would discuss and we would just let the rest of the family know. I'm a firm believer in, you know, I believe in talking to family members and getting their opinion and all that good stuff, but I'm just not one for asking a bunch of people. So, because we do have legal power of attorney, we just kinda made the decisions ourselves and informed everybody else of what was gonna be.

Consistently among the CGs, there were family discussions of varying degrees that were an important part of the decision-making process. Those discussions sometimes involved disagreements or differing opinions. Consensus was reached in some cases. In other cases, it was not the goal of the family communication.

Shaping the Decision

Various factors were involved in shaping the CGs' decision to use hospice services. Some had a direct influence, while others were simply involved in the process, and, in some cases, served as a support during the decision-making process. The following subcategories were all factors that helped to shape the CGs' decision to use hospice care for their loved ones.

Knowing and learning about hospice. Knowledge about hospice was important since it allowed the CGs to make an informed decision. The data showed that most CGs had little or no knowledge of hospice and the services offered when it was initially introduced to them. Of the 18 CGs, three understood the purpose of hospice and the services offered. Of those three, two had used hospice in the past for loved ones, and one had knowledge from her work experience in a physician's office.

When CGs were asked to describe their knowledge about hospice prior to their current situation, their answers reflected their lack of knowledge or what they heard from others and believed it to be. One CG simply stated, "Nothing." Another said, "Hospice is one foot in the grave and one foot out…you're just getting them ready for death." Yet another stated, "I've heard a lot of people just speaking of hospice. But, I know that the only thing I knew that people go there when they get sick. But I really didn't know the real meaning of hospice."

This lack of knowledge or limited knowledge was prevalent among the CGs. As a result, they had to gather further information about hospice to make their decision. This information came from various sources, including HCP, hospice representatives, and the internet. Sonya stated that she got hospice information from the physician, "The doctor told me…he told me everything, he said hospice was furnished with everything he [her husband] needed." Other members of the healthcare team also provided information.

Sarah spoke with a chaplain and a caseworker. She stated, "So we asked the chaplain…we asked him about some of the hospice services they have…and that's when he went on to, to explain some more details, along with the case worker." Terri's information came from a hospice representative. She explained, "One of the hospice reps who come by to see my doctor that I work for sat down with me over lunch one day and gave me an explanation of things that I did not know." Sheryl explained that she turned to the internet to learn more about hospice services, "I downloaded all kinds of information, and of course AARP has tons of information." Once they gathered the necessary information, CGs could then share it with family and proceed with the decision-making process.

Being leery about hospice. Many CGs expressed uncertainty about hospice when it was initially presented. The reasons for the uncertainty varied, and included their lack of knowledge, negative previous experience, initial communication with the HCP, or some initial mistrust. Terri spoke of her lack of knowledge about having her grandmother at home. She described not knowing what exactly would happen if she were to choose home hospice. She stated, "I did have concerns, and that concern was what happens, let's just say her PEG tube came out, what are we to do? Are we to bring her to the hospital or call hospice?"

Barbara described her previous negative experience with hospice as the reason for her uncertainty, "Well, I was leery at first simply because of what I'd experienced beforehand. The hospice is just something that you've all but given up and you're just trying to make their life simple." Barbara also stated that her sister had been previously admitted and discharged from hospice. Her sister had developed a bedsore during the previous admission, hence her reservations when it was suggested a second time. Samantha explained her reservation related to her discomfort with her initial communication with a hospital caseworker. She stated, “I felt like they were rushing me to make a decision, so I wasn’t sure about it [hospice].”

For two CGs, mistrust related to finances was cause for uncertainty about the hospice option. Precious explained her reaction when told that no further chemotherapy would be done and hospice was introduced. She explained:

> As soon as they said that she [physician] wasn’t doing no chemo, that chemotherapy wasn’t working, the first thing I said out of my mouth was, ‘Yeah, because this is how y’all do poor people, you give the weakest chemotherapy treatment that you can, it’s more water in it than anything.’

Precious relayed that her mistrust was related to her experience earlier in her mother’s illness, when she had difficulty securing home care for her mother. She believed the difficulty was because of her mother’s insurance coverage. She also attributed some of her mistrust to her emotional state. She explained, “I know it was different emotions I went through while she was there. I would get mad at the doctors.”

Cecelia explained that with the admission of her friend to a private hospital, she believed that the suggestion of hospice was related to finances. “My first impression was, when they explained it [hospice] was, well yeah you [the patient] got Medicaid, so ain’t nobody gonna benefit from this.”

No one reason for uncertainty or reservations was common among the CGs, their reasons varied. However, many cited the need to make their loved ones comfortable and to meet all their caregiving needs, as reasons for overcoming these reservations and moving forward with the decision-making process for hospice use.

Taking care of their loved one. This subcategory addresses the CGs’ ability to provide the physical and medical care needed for their loved ones, and their desire to make their loved ones comfortable. The majority of CGs cited these two issues as directly influencing the decision to use hospice and the selection of inpatient or home hospice.

For some CGs, their loved one's physical condition was a predominant factor in considering the care needed. They realized that hospice could provide the complete care needed for their loved one, or to supplement the care that the CG and family were able to provide at home. For others, there were personal preferences of either the CG or the patient as it related to home or inpatient care. Jaye spoke of her sister's condition and the physical demands of caring for her that she was unable to provide. She explained:

> Well, because of her weakness and her loss of muscle tone, she was not able to move, she is, it's like picking up dead weight…so there was no way I would be able to lift her to put her on a pot, or do anything.

This led to Jaye's choice of inpatient hospice care.

Sarah was aware of the physical demands of her father's care but her mother insisted that he be cared for at home. She stated, "She [her mother] wouldn't bend on that [bringing him home] …but there was so many of us that we could tag team it [his care]." Sarah and her siblings could share the care that was needed, in addition to the care provided by home hospice services.

Sonya explained that she was the only one available to care for her husband at home and she wanted to keep him at home; however, it was physically demanding for her. She described her situation this way:

> It was just hard for me to give him a bath, and it was really hard for me to keep him dry and clean. I couldn't do the things they wanted me to, like pull the sheet and flip him like that.

Sonya realized that the assistance she needed to keep her husband at home could be provided by hospice; hence her decision to accept hospice care.

Caring for their loved one also involved making that person comfortable and honoring their wishes, if those wishes were known. The majority of CGs stated that the desire to keep their loved ones comfortable was a direct influence on their decision to use hospice services. John reported that his grandmother was in severe pain and the need to make her comfortable. He stated, "She was in such bad condition…at this point it was like she was in excruciating pain…she was in too much pain to do anything besides get her pain medicine." John and his family decided that hospice would provide the necessary pain control to make his grandmother comfortable. Mary also reported her husband's comfort as a major factor in her decision. She stated, "I think the main thing was I wanted him not to suffer." Derrion also stated that the hospice decision was based on their ability to keep her cousin comfortable. She explained:

> So, that's why we made that decision to send him there [hospice facility], cause they said, 'We will make him as comfortable as we can'…they gonna do the best that they can so that he can, he's comfortable…that he can die in peace.

A few CGs' loved ones stated that they no longer wanted to continue with curative treatment and just wanted to be comfortable. While those patients did not specify hospice care, the CGs decided that hospice would be the way to honor their loved ones' wishes. Only one patient who made his wishes known had a living will that specified his desire not to be kept on life support. Jaye's sister was clear in her decision to stop treatment. Jaye stated:

> She point blank told them she didn't want any additional care, so there was nothing else the hospital could do…she was very clear and adamant that this is what she wanted…the only person I care about is her, and whatever she asks me to do, I will do it.

Jaye decided on inpatient hospice for her sister to honor her wish of being comfortable.

Precious described being reminded of past conversations she had had with her mother, prior to her current illness, when her mother made her wishes known:

> A couple of people reminded me. They said, 'Just listen to what mommy say' because in her right mind she said, 'Hey, I don't what to suffer, and I don't want to be cut on. I don't want them cutting on me.' That was the only action, basically, to cut her open in the spine part.

Being reminded of this past conversation where her mother specified her wishes was integral to her decision to use hospice services.

Antoinette was the only CG to have a living will for her husband. She stated that choosing hospice was her way of honoring her husband's wish, specified in his living will, not to remain on life support. She explained, "It was his decision, his decision I really didn't like, but that's what he wanted…I would rather him be on life-support the rest of his days." Despite her disagreement, honoring her husband's wishes was important to her.

Caring for their loved ones by making sure they had adequate physical care, were comfortable, and had their wishes honored directly influenced the decision to use hospice services. CGs also described various emotions as they were making the decisions related to caring for their loved ones.

Feelings about EOL and hospice. CGs described feeling various emotions as they moved through the decision-making process. Their feelings were related to realizing that their loved ones were at the end of life and the decision to use hospice, which represented a change in the focus of care from curative to comfort care. The common feelings described were hurt, sadness, and a sense of loss.

Jake described being aware that his mother's prognosis was not good based on her previous medical history. He described how he felt in this way:

> Well, I was sad heading down there [the hospital] when she had this last stroke, because I was with her at her doctor's appointment and that's when they told me that if she had another stroke, they said that if she had another one, that was going to take her.

After he arrived at the hospital, his conversation with the doctors confirmed the fact that his mother was at the EOL. He spoke further of his sadness, "I was just very sad…I just knew mama wasn't going to come back with us, it bothered me." After speaking with the physicians, he thought about his mother's strength over the years through many crises and of the close relationship they had. He stated, "Yeah, she was my one in the hole right there, because my family, we went through a lot of bad crises…mama really caught it taking care of us…I was just sad."

Sarah also described sadness; however, her sadness came after making the hospice decision, which reinforced the finality of her dad's condition. She explained, "I was sad, I don't know any other words to say. I was really, really sad, I was really sad. Yeah…it was the feeling, I knew I was losing my dad."

Jaye's emotions were also related to her sister's choice to discontinue further curative treatment; a decision that meant she was going to die. Jaye described feeling hurt and a sense of loss as she discussed her sister's wishes with the physicians:

> It just kinda hurt me that she wants to go…I'm really torn up on the inside about my sister choosing to die at 63…it's not difficult for me that she chose it, so much as my sister's still young, and personally I felt she should've fought harder. But I understand where she is.

The CGs described these important and intense emotions. However, these emotions did not appear to have a direct impact on the decision to use hospice, but were nonetheless involved in the process. To cope with their emotions and the entire decision-making process, most CGs turned to their spiritual and religious beliefs.

The Lord has me. All CGs reported a religious affiliation that guided their spiritual life. While their spiritual beliefs and religious practices were involved in the decision-making process, those beliefs and practices did not directly influence the decision to use hospice services. Many CGs described spirituality as a support and something that guided them as they moved through the decision-making process. One CG stated that her spirituality was not involved in the decision-making process at all. When asked how spirituality or religion played a role in the decision to use hospice, Mildred, whose husband, the patient, was a pastor described it as a support.

> If you believe in Jesus Christ you have to believe in your spiritual convictions. My pastor was hand in hand with us…it wasn't a thing where he [her pastor] offered any kind of suggestion or opinion he was just there basically for spiritual support not necessarily to give any input into what you should do or should not do.

Jane described how her spirituality intertwined with taking care of her sister during her illness, but making her comfortable at the EOL was more of a physical necessity. She explained:

> For a long time, I would push her to get out of the bed, why spend so much time in the bed? Finally, I think the Lord helped me realize that she was a very energetic person and that she was in the bed because she didn't feel well…we believe God and you know, you pray as hard as you can, but then there's stuff you have to do in the physical, we were doing all of that, we were making sure she was comfortable.

Mary Ann spoke of her spirituality guiding her and her husband through the hospice decision for their niece:

> Our faith is what makes us strong, not even make us, but our guidance through the Holy Spirit. We didn't feel like we had to consult anybody. I just said, 'Honey, we're going to do it. I got you, don't worry, I got you.' I knew the Lord had me, so I was like, let's do it, let's roll.

Mary, whose husband (the patient) was an elder in the church simply stated, "No, that [spirituality] didn't influence my decision at all." For the majority of CGs, spirituality emerged as a source of support and guidance and did not have a direct influence on their decision to use hospice services.

Selecting Hospice Service

Once the decision was made to use hospice services, CGs and families went through the process of choosing a hospice delivery agency and the care that would meet their needs. The fourth category, selecting hospice service, depended on the communication with hospice personnel, the decision to use home or inpatient services, and the choice of available hospice agencies.

Talking with hospice representatives. Communication with the hospice agencies was important in the selection process. For many CGs, it was their main source of information about hospice services. All CGs and families were given an opportunity to speak with hospice representatives about the services offered before either making the choice of agency or accepting services from the agency. Most CGs described good communication that was very informative. CGs described the fact that hospice representatives took the time necessary to explain all details related to their services. Buck explained his satisfaction with the explanation and the time spent:

> They had a representative to come out from hospice after we inquired, and again, she sat us down for two or three hours and explained every single thing involved with the whole hospice process. We were impressed by it.

Precious explained similar detail in the information that she received from the hospice representative. She stated, “They sent an outreach worker to sit with us and talk about what they do, it was very nice.” Jane also described the detail of the information she received. She said, “They explained very thoroughly what they were going to do and what to expect.” Most CGs were satisfied with the information they received from the hospice personnel. For those who wanted inpatient services, they were given the opportunity to visit the agencies before making a final decision.

However, two CGs were dissatisfied with the communication of the hospice representatives. The two CGs described their communication as that of a salesperson or being misled. Sheryl described the representative's tone as being one of a salesperson. She reported, "Of course they [hospice representative] came in being fresh, and oh no, no, you know, selling the service, saying, 'It does not mean somebody's going to die'" Sheryl reported feeling as if they were being sold a "resort." While Sonya did not describe the sales atmosphere, she felt she was misled by the hospice representatives when she was told that going into hospice did not mean that her husband was going to die. For CGs, communication with these hospice representatives was important in facilitating the choice of hospice agency; it was also a main source of hospice information.

Deciding between coming home or going to a home. This subcategory describes the decision that CGs had to make between home hospice care and inpatient care. When deciding on an inpatient hospice facility or home hospice care, CGs considered different factors. As explained earlier in the category of taking caring of their loved ones, many CGs considered their ability to provide the care that their loved ones needed. Their ability to provide this care was directly related to the decision for home or hospice care. For Sonya, even though she recognized that she had difficulty with her husband's physical care at home, she insisted on bringing him home, "I told them, I didn't want him in no home ever. He was coming home with me."

A few CGs considered the wishes of their loved ones by involving them in the decision about home or inpatient care. Mildred's husband was involved in the decision by directly stating his wishes. She stated, “My husband said ‘I want to come home,’ so that I didn’t even inquire into him going to a hospice facility.” Similarly, Mary’s husband was involved in the decision through conversations that they had. She explained, “My husband realized that he wasn’t going to recover. We ourselves talked about hospice and where he would want to go.” She further discussed her reason for choosing inpatient care:

> I wanted a nurse to be able to come whenever it was needed, and if you do hospice at home sometimes that can’t happen, so you may be waiting a day or two before that nurse can come. Whereas with inpatient, the nurse is there, and a nurse can come you see, because they’re already there…one of the benefits of hospice at home is that the person is dying in a familiar place, it’s home, but the other side of that is you may not get the best care that he can get if he’s at home.

Choosing a hospice agency. The choice of an agency to deliver care was important in the decision-making process. CGs were divided almost equally on whether they were given a choice between agencies. Sheryl spoke of being given a choice when she spoke with the first hospice representative. She stated, “We did have options. They was like, ‘You don’t have to use us, there’s other ones if you want to look into other hospices.’” Barbara explained her choice for her sister who was already a patient in a nursing home:

> It was a couple of them that directly worked with the nursing home that she was stationed at. Of course, they told me that I could choose my own, I could go somewhere to get someone else if I chose to…I found no reason not to choose from the two the nursing home had working with them and so that’s what I did.

Mary explained her choice by stating, “They gave us several to choose from, but because of my experience with the one that we chose, we chose to go with that one.” The reasons varied for those who were not given a choice. Jake reported a lack of available beds in other hospices, so he was directed to the facility that had open beds. He stated:

> Well, they the one, the doctors told us when they found a place…they said a lot of them was full, but [name] was the one they found that could take her, and that was a clean facility. It smelled nice, it was just kept up around there.

Buck also explained that he was not given a choice of agencies, “She [the nurse] told me the number to call and that’s what I did and they sent a representative right out, and she gave us a rundown…we just had that one.” Terri explained that a choice of agencies was not necessary because she had already chosen an agency based on her work experience:

> It [choices] was not presented to us. I believe because of the position that I’m in where I’m the office manager for this doctor’s office, there’s always been a particular hospice company or rep that just always stuck out to me since I’ve been in my position…to me a clear sign to just when it came time for hospice, we’re going to go ahead and stick with the same company…I knew the quality of work that they do.

CGs who were not given a choice of agencies did not report any dissatisfaction with not having a choice; however, all CGs stated that they would recommend to others that they evaluate different agencies before deciding. Selection of hospice services is important because it can be viewed as a part of the outcome of the decision to use hospice care.

Experiencing Hospice

This category describes the CGs’ expectations as opposed to their experiences with hospice care services after the decision was made and their love one was transferred to the facility.

Getting what they expected. CGs’ experience with hospice care is important because it impacts future decisions to use hospice for themselves or other loved ones, and whether they would recommend hospice to someone else in a similar situation. Along with their actual experience with the care given to their loved ones, CGs also relayed their expectations of hospice as it related to their experiences. A majority of the CGs’ experiences lived up to their expectations and the experiences were positive. Jane explained that her expectation of hospice matched her experience:

> That we could expect somebody to come in just to help with bathing and like that…everything they promised us they would do, they did. A nurse three times a week to give her a bath, clean up the bed…they really did embrace me well.

Terri explained some initial inaccuracies of her expectations, which were later clarified by a hospice representative. Despite these inaccurate expectations, she was satisfied with her experience. She explained:

> My expectation at that time was that someone would come out to make daily visits…maybe a doctor or nurse practitioner or something, would come out…one of the hospice reps gave me an explanation though of how everything would work...it's really been an easy process since she's been on hospice. A lot easier than what I thought it was gonna be you know.

Buck also described his experience as exceeding his expectations, "Oh, we've gotten much more than we expected…we were very impressed." Most CGs reported positive experiences with hospice; many of them stated that the experience exceeded their expectations. Because of these experiences, CGs stated that they would use hospice for themselves and would recommend hospice to friends and family if needed.

The open coding phase of this analysis revealed five major categories and their corresponding subcategories. This phase of analysis also uncovered the major theme or core category of the study—realizing the end of life. In the next phase of grounded theory analysis, axial coding, the relationships between these categories, subcategories, and core category are further developed.

Axial Coding

The five primary categories developed during the open coding phase were (a) realizing the EOL, (b) hearing and believing, (c) shaping the decision, (d) selecting hospice service, and (e) experiencing hospice. An axial coding paradigm was created during this phase of analysis to show the relationships between these categories, subcategories, and the core category. The axial coding paradigm, illustrated in Figure 4 depicts the core phenomenon of realizing the EOL, and its relationship to the conditions, contexts, strategies, and consequences that emerged from the data.

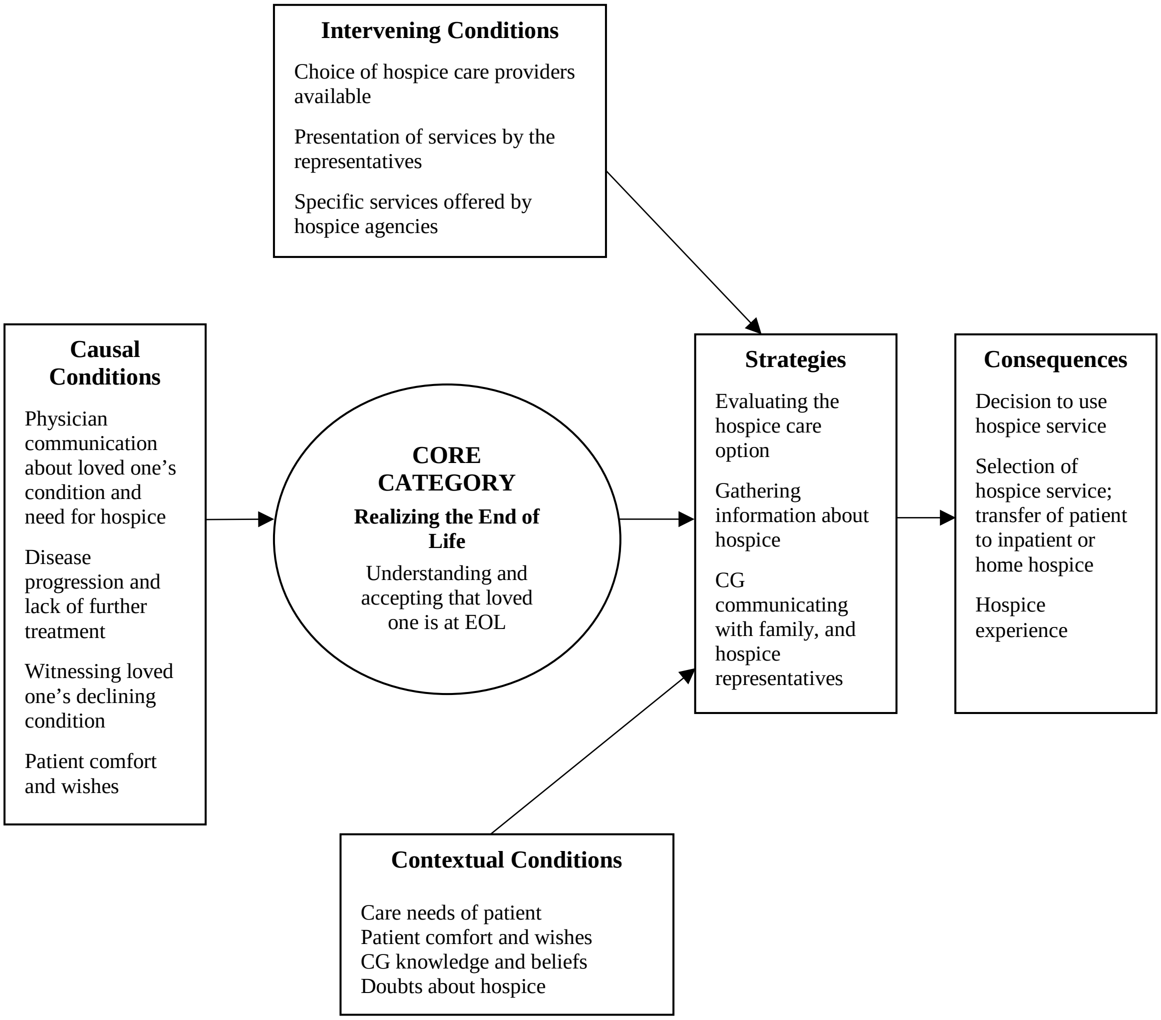


Figure 4. Axial coding paradigm of African American caregivers' decision to use hospice services for a loved one.

Core Category

The core category or phenomenon, also known as the central category, is the main theme of the research (Corbin & Strauss, 2015). Other categories are linked to this core category in the process of creating the theoretical model. In this study, the category that emerged as the core phenomenon is realizing the end of life. This category reflects the CGs’ understanding and acceptance of the prognosis that their loved one was at the EOL.

Recognition and acceptance for some began with an initial disbelief that their loved one was at the EOL. Others reported that the intensifying of their loved ones’ symptoms prompted that recognition. Yet others described that the process resulted from being there and witnessing the decline of their loved ones. The majority of CGs went through the process of understanding and acceptance of their loved ones’ prognosis. Once the realization was made of the finality of their loved one’s condition, the decision to accept hospice as an option and act on that acceptance occurred.

Causal Conditions

Causal conditions are factors that lead to the core phenomenon (Corbin & Strauss, 2015). The causal conditions that emerged among this population were (a) physician communication about their loved ones’ condition and recognizing need for hospice, (b) the disease progression and lack of further treatment, (c) witnessing the decline of their loved ones’ condition, and (d) the comfort and wishes of their loved ones. Physician communication with CGs about their loved ones’ condition and the relationship between the CG and the physician were integral to CGs’ process of recognizing and accepting that their loved one was at the EOL. For many of the CGs, information from the physician was the first introduction to the idea of hospice and the idea that their loved one was at the end of life. Therefore, the way this information was conveyed to the CGs by the physician was of utmost importance to the decision-making process. The majority of the CGs reported confidence in the physicians and trust in the information given to them. Hence, it was easier for them to accept that their loved ones were at the end of life.

Conversations with the physician also included the extent of the patients' disease progression and the lack of further curative treatment options. One CG reported a number of procedures to help reduce the cancer in her husband's lungs but eventually realized these procedures were no longer effective as his disease progressed. Another reported watching the decline of her father's condition over several hospital stays and particularly during the last visit prior to his admission to hospice. She noticed that his condition was not getting any better and she needed to accept that he was at the end of his life. Yet another reported that along with his knowledge of the disease process that had plagued his loved one for many years, he could see her decline in recent months and realized that she was approaching the end of her life. For a few CGs, it was their loved ones' wish to discontinue further life prolonging treatment and to be made comfortable. These two factors emerged as the impetus for the core phenomenon of the realization of the end of life that began the decision-making process to use hospice services.

Strategies

Strategies, also called actions-interactions, are defined as the responses to the core phenomenon (Corbin & Strauss, 2015; Creswell, 2013). Strategies for this population included (a) evaluation of hospice care as an option, (b) gathering information about hospice through communicating with hospice representatives and other means, and (c) communicating with family members about the patient's condition and hospice care.

Evaluation of hospice as an option occurred following the understanding that their loved one was at the EOL. In most cases, the information about the patient being at the EOL was presented simultaneously with the hospice option. CGs evaluated the hospice option from a conceptual and pragmatic standpoint. For the majority of CGs, there seemed to be an understanding that in addition to the physical and medical assistance that hospice would provide, there was an understanding of the hospice concept, which provides family support and lessens their loved one's suffering. They reported wanting that family support but most of all were interested in making their loved ones comfortable. So, for them hospice as an option was both conceptual and pragmatic. For two of the CGs however, the consideration of hospice was more pragmatic because their decision seemed to be solely based on the physical help the hospice would provide for their loved ones' care.

To evaluate the hospice option further, CGs and their families spoke with hospice representatives. Most of the hospice information that CGs received came from these representatives. CGs and families gathered all the necessary information and had discussions as to what the decision would be.

Intervening Conditions

Intervening conditions are broad situational factors that influence the strategies taken in response to the core phenomenon (Corbin & Strauss, 2015). In this study, the intervening conditions that affected the strategies consisted of (a) the choices of hospice care providers available to the CGs, (b) the presentation of those services by the representatives, and (c) the specific services offered to meet the patient and family needs. Some families had choices of hospice providers and could speak with representatives of those services and, in some cases, visit the facilities. One CG used a provider based on previous use. That CG also reported having a previous discussion with her husband, the patient, who stated that should the need arise, he wanted to use that facility. Another was told by the hospital representative that there was only one facility in the vicinity with beds available for immediate transfer. They visited that facility and were satisfied that it was the right choice.

CGs also reported that their conversations with the hospice representatives played a part in the decision to use that service. Most were satisfied with their discussions with the hospice providers and the presentation of the information, except one who felt as if they were being sold a “resort” type service. All the hospice agencies were able to provide the appropriate level of inpatient or outpatient care depending on the need or preference of the families.

Contextual Conditions

Contextual conditions are specific situational factors that influence the strategies (Creswell, 2013). Those factors in this study were the wishes of the patient, the CGs’ desire to lessen the suffering of their loved ones, the CGs’ knowledge and beliefs about hospice, and any doubts they had. CGs reported wanting to honor the wishes of loved ones who stated that they did not want to participate in any further curative treatment. They also stated that they did not want their loved ones to suffer. Hospice could provide the solution to both desires; it provided an alternative to curative treatment where their loved ones would be made comfortable and die peacefully. CGs did report some reservations and uncertainty about hospice when it was first introduced by the physicians.

CGs' reservations seemed to result from a lack of or little knowledge of hospice, some initial bad communication with HCP, and initial mistrust related to finances.

Consequences

Consequences are the outcomes of the strategies used (Corbin & Strauss, 2015). The consequences in this study were (a) the CGs' decision to use hospice care, (b) the patient's admission to either home hospice or an inpatient hospice facility, and (c) the overall hospice experience. Most CGs could overcome their initial uncertainty and make the decision to use hospice care. Transfer to hospice was generally seamless; however, two families had trouble with the initial set up of care at home.

The hospice experience for most of the families was satisfactory. Two families were not satisfied with the care they received. One family's loved one was initially transferred to an inpatient facility, but after some time, transferred to home care because of dissatisfaction with care and the patient's wishes to return home. In most of cases, the care met and exceeded the families' expectations.

Selective Coding

The selective coding phase of this study resulted in the development of the conditional matrix, the theoretical model, and related propositions that further explain the derived model.

Conditional Matrix

The diagram in Figure 5 represents the matrix that emerged during the selective coding phase of this study. At the core of the matrix, in red, is the realization of the end of life—a realization that all caregivers came to in the initial stages of the decision-

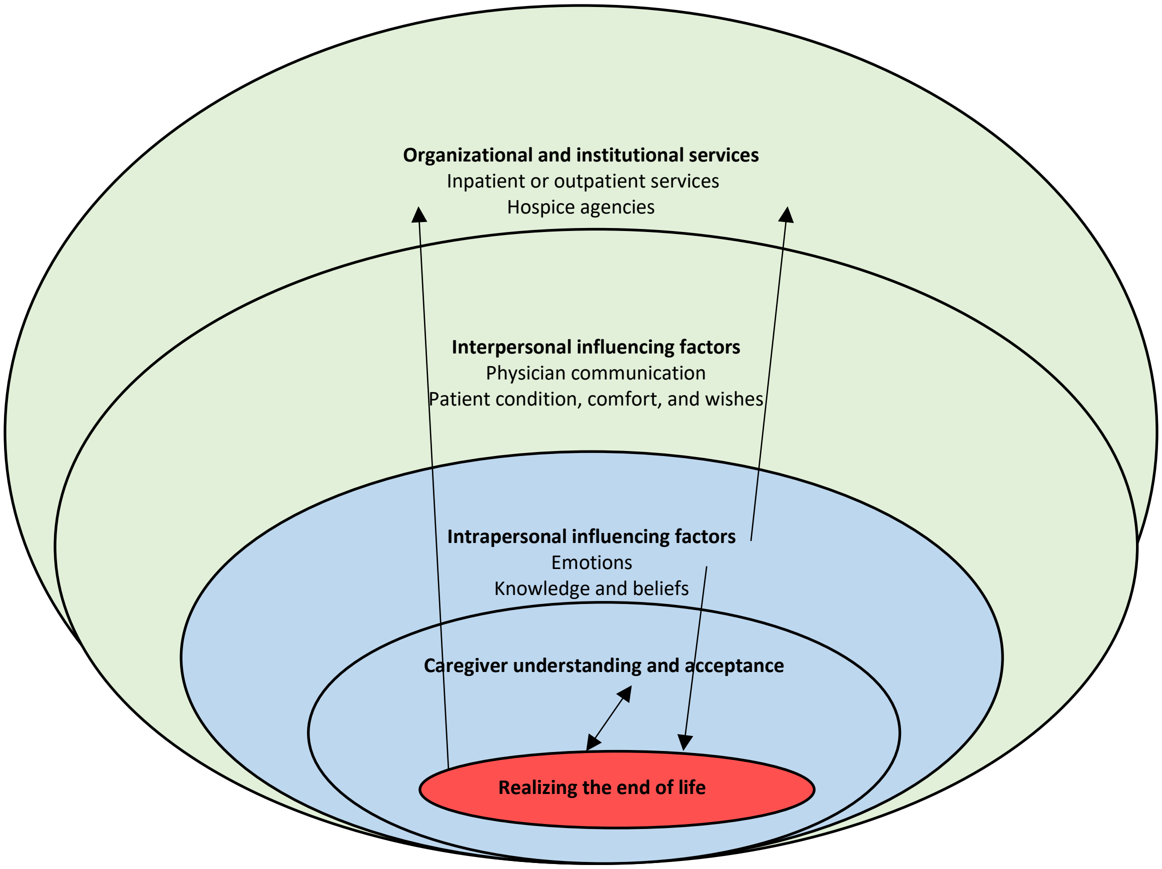
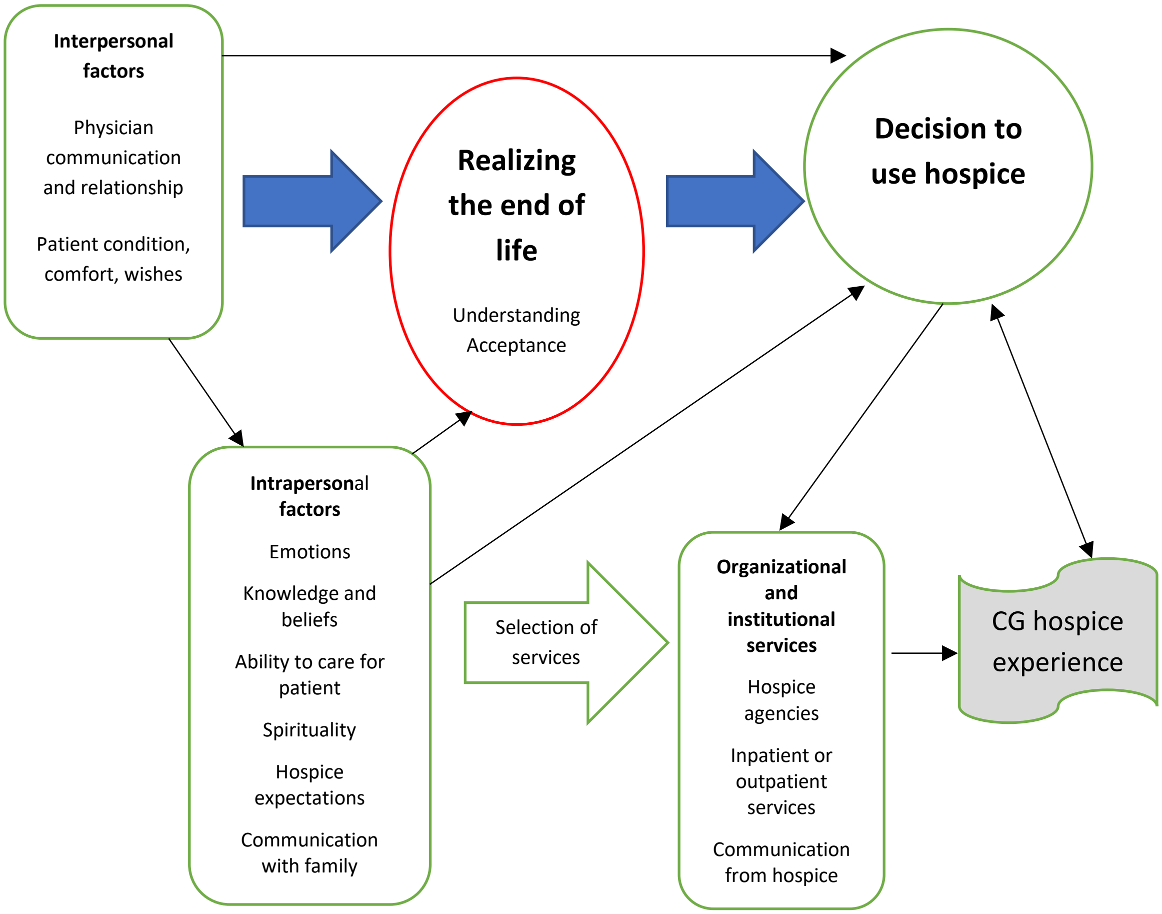


Figure 5. Conditional matrix of African American caregivers' decision to use hospice for a loved one.

making process—and that all other factors were dependent upon the decision to use hospice. The next set of two blue rings, categorized as intrapersonal factors of influence, represent micro conditions that emerged. These conditions were in the control of the caregiver and included understanding and acceptance of the loved one's condition, emotions, knowledge and beliefs about hospice care, spirituality, communication with other family members, and expectations from hospice. The rings outlined in green represent macro conditions that emerged outside the control of the caregiver, categorized as interpersonal factors of influence. These included caregiver communication and relationships with clinicians and family, and the patient's wishes and comfort. Also included in the macro conditions are organizational and institutional services, which included the hospice agencies and the services available for selection by the caregivers and families. Examples of the specific micro and macro conditions are listed within each circle. The arrows illustrate the relationships that exist between the conditions. These conditions do not exist in isolation and are at times dependent on each other such that a change in one condition could result in a change in other conditions.

Conceptual Model

In the final stage of selective coding, a model of African American family caregivers' decision to use hospice services for a loved one was developed building from the axial coding paradigm and the conditional matrix. The model by no means represents the hospice decision-making process of all African American family caregivers. It instead presents an insight into the process for the participant group of African American



caregivers in this study, a process that will require further research. The model derived from this study is shown in Figure 6.

Figure 6. Conceptual model of African American caregivers' decision to use hospice services for a loved one.

The decision-making process begins with HCP, primarily physicians, introducing the prognoses of their loved ones and the option of hospice care to CGs simultaneously. The CGs considered this communication and their own observations of changes in their loved one as they came to the realization that their loved ones are at the EOL. Realizing that EOL is approaching is at the core of the hospice decision-making process, and entails understanding and an internally processed acceptance of the EOL prognosis. Once CGs came to the realization of their loved ones' prognoses, they were then able to evaluate hospice care as an option and make the decision about its use.

Although the core process of realizing is initiated predominantly through physician communication with the CG about their loved ones' prognoses, there were other contributing factors, including witnessing their loved ones' declining condition, disease progression, and realizing that there were no further curative treatment options. The realization process was influenced by factors broadly categorized as intrapersonal and interpersonal. Intrapersonal factors are within the control of the CGs, such as their ability to care for their loved ones or their knowledge and beliefs about hospice. Interpersonal factors are those factors outside of the CGs' control, such as their communication with the physicians or their loved ones' condition. These factors vary in their level of involvement and influence on the core phenomenon and the decision to use hospice care. Some of the interpersonal factors also had an impact on the intrapersonal factors of the model. For example, the interpersonal factor of the patient's condition directly affects the CG's ability to care for the patient, an intrapersonal factor.

The model also allows for the three CGs who did not follow the path of the others. They understood their loved ones' prognosis but did not accept it; however, they made the decision to use hospice, so the realization phase was not complete before the hospice decision was made. These CGs had differing reasons for making the hospice decision. One cited the physical care needs of her husband as directly influencing her decision. Another CG had a living will document that stated that her husband did not want to remain on life support. Hospice allowed her to honor his wish by making him comfortable. The third CG reported that the hospice decision was made by the patient and she went along with it to honor her friend's wish.

Once the decision to use hospice was made, CGs began the selection of a care delivery agency, and the choice of inpatient or outpatient service. Some CGs were given a choice of hospice agencies and others were directed to an agency by HCP. Choice of inpatient or outpatient services was primarily dependent upon the care needed by the patients and the CG and families' ability to meet those needs adequately. CGs communicated with hospice personnel about services offered and the needs of their loved ones. For those who chose inpatient services there was the opportunity to visit the facilities before deciding on an agency. The CGs' experience with hospice care after the decision was made is also included in the model because it directly influences future decisions to use hospice care for themselves or other relatives, and if they would recommend the service. CGs evaluated their experience based primarily on their expectations of the hospice delivery agencies.

In summary, the model resulting from the data shows the introduction of the EOL condition of their loved one, followed by realizing the prognosis, and subsequently deciding to accept hospice care. At this point, decision making included the selection of the appropriate service that would meet the needs of the patient, the CG, and the family.

Propositions

The final step of this analysis was delineation of propositions or hypotheses that helped to further explain the study results and the general relationships of the concepts established in the model. Below is a list of propositions that further describe the process of African American CGs' decision to use hospice services for their loved one.

1. Realizing the end of life is at the core of the CGs' decision to use hospice services.
2. Hospice as an option is initiated primarily by physician communication.
3. CGs' understanding and accepting the end of life of their loved one is initiated by physician communication, patient comfort, disease progression, or declining condition.
4. CGs' decision to accept and use hospice services is dependent on understanding and accepting the end of life of their loved one.
5. Spirituality is used as a support for the decision to use hospice services.
6. The interpersonal factor of their loved ones' comfort directly influences the CGs' decision to use hospice services.
7. CGs' communication with immediate family members influences the realization of their loved ones' prognoses and the decision to use hospice.

8. CGs’ hospice experience affects their decision to use hospice in the future for themselves or a loved one.

Summary

Five categories emerged from the study data: (a) realizing the end of life, (b) hearing and accepting, (c) shaping the decision, (d) selecting hospice service, and (e) experiencing hospice. Further analyses of these categories and subcategories through the processes of open, axial, and selective coding yielded a conceptual model of African American caregivers’ decision to use hospice services for a loved one. Through these analyses, realizing the end of life emerged as the core phenomenon in the conceptual model. A variety of factors influenced and/or was involved in the decision-making process of African American CGs to use hospice services for a loved one.

CHAPTER 5

DISCUSSION

This chapter contains a discussion of the study results. The research questions and propositions are addressed, and compared and contrasted with existing evidence. The conceptual model, generated by analysis of interview data using a ground theory approach, is discussed. Study limitations, recommendations for future research, and implications for nursing practice also are addressed.

Central Research Question

The study sought to answer the central research question: What is the decision-making process of African American family CGs' decision to use hospice services for a loved one?

The conceptual model depicted in Figure 6 illustrates the common path taken by most caregivers to make a decision to use hospice. The model was generated through analysis of the data, using open, axial, and selective coding, and shows the introduction of the EOL condition of their loved one, followed by the realization of the prognosis, and the subsequent decision to accept hospice care. At this point, the decision making moved to the selection of the appropriate service that would meet the needs of the patient, the CG, and family. While this process may seem linear, several factors were involved, with varying levels of influence at different stages in the process. The non-linearity of the model is evident in the outlying cases that emerged. Outlying cases are those that represented a variation in the theory and may seem contrary to the process (Strauss & Corbin, 1998). In this study, three CGs did not go through the process of realizing their loved ones were at their EOL; however, they, for different reasons, made the decision to use hospice.

Research Subquestion 1

> What is at the core of African American family CGs' decision-making process to use hospice services for a loved one?

Realizing that their loved one was at the EOL was at the core of the decision-making process for the CGs. Fifteen of the 18 CGs reported coming to this realization, which led to the decision to accept hospice as an option. Previous research described similar findings, where CGs' understanding and acceptance of the finality of their loved ones' prognoses resulted in a change in mentality that propelled them into the stage of final decision making (Lewis, 2014; Meeker, Waldrop, Schneider, & Case, 2014; Waldrop, Kramer, Skretny, Milch, & Finn, 2005). Physician communication about their loved ones' condition was the primary precipitating factor of this realization. However, other contributing factors, such as disease progression, the lack of further treatment options, witnessing the decline of their loved ones' condition, and symptoms intensifying are consistent with previous findings (Lewis, 2014; Meeker et al., 2014; Waldrop et al., 2005; Waldrop & Meeker, 2012).

Research Subquestion 2

> What factors facilitated and impeded African American family CGs' decision to use hospice services for a loved one?

The common factor that emerged as the facilitator of the decision-making process was communication. CGs consistently reported that their communication with the physician and hospice personnel gave them information that facilitated their decision making. Physicians were the initial and primary member of the healthcare team to introduce hospice as an option to the CGs. Many CGs reported that they had very little or no knowledge of hospice prior to their conversation with the physician. Hospice was introduced simultaneously with information about the patients' prognoses. Therefore, physician communication was integral to the core of the CGs' decision-making process, realizing the EOL, and the actual decision to accept hospice as the next step in care.

Most CGs believed that physicians were genuine in their communication. They reported receiving clear information from the physicians about their loved ones' condition and the hospice option. Effective physician communication fostered trust for the majority of CGs, which made receiving the information easier. CGs reported ongoing open communication with the physicians throughout the course of their loved ones' illness, and the development of a trusting relationship prior to their loved ones reaching the EOL stage. This communication and relationship made the EOL and hospice discussion easier to accept. In a few cases, there was more than one physician involved, and in those cases, CGs reported that all the physicians were on the same page and presented the same information that facilitated understanding and acceptance.

Communication as a facilitator in this study also extended to other HCP, particularly hospice personnel. The communication with hospice personnel provided information about the services offered by hospice that CGs needed to make their decision. Most CGs reported that they received honest, detailed communication from hospice personnel, which made clear all the services that would meet their needs. However, two CGs were not satisfied with the hospice communication. One felt they were being sold a service, while the other felt that she was misinformed about some of the services she would receive. Overwhelmingly though, CGs reported that learning about these services in a clear, comprehensive manner from the hospice personnel facilitated their decision making.

Communication with hospice personnel and written material allowed CGs to learn that hospice afforded the means to make their loved ones comfortable and decrease their suffering. CGs also learned that hospice could provide the physical and medical care that their loved ones needed that they were not able to provide. For some who wanted to keep their loved ones at home, hospice supplemented the care that CGs and families could provide and made remaining at home possible. Others, who were unable to keep their loved ones at home, used the inpatient services offered by hospice to provide the care needed.

Yancu et al. (2015) examined the attitudes and beliefs of AA about death and dying and found that participants believed hospice was an appropriate option when the CGs needed assistance with care of the patient. Previous research supports the concept that open and honest communication between patients and their families and the HCP improves adherence to treatment and enhances the treatment experience by improving the support they received from those family members (Song, Hamilton, & Moore, 2012). However, prior research has also shown that poor communication can be a barrier, particularly at the EOL, and can lead to increased decision-making conflict among AA patients and CGs (Dillon & Basu, 2016; Smith-Howell, Hickman, Meghani, Perkins, & Rawl, 2016).

In the current study, the majority of CGs did not report a single factor that impeded the decision-making process. When asked about impediments, the majority of CGs responded that there were none. For those who spoke of impediments, they described the initial confusion they felt when first they were told their loved one was at the EOL. One also described wanting to wait on God to make the decision. However, these CGs were quick to explain that these thoughts were short-lived, and were overshadowed by their recognition that their loved one was dying, and a subsequent desire to make them comfortable. Prior research has identified various impediments to AA decision to use hospice services, such as communication, denial of terminality, spiritual beliefs, and a lack of knowledge (Reese, Smith, Butler, Shrestha, & Erwin, 2014; Yancu et al., 2015). None of these impediments were corroborated by the current study.

Research Subquestion 3

> What are the available resources used by African American family CGs' in their decision to use hospice services?

In the current study, CGs used resources related to information gathering, and the social support of immediate family as part of their decision making. As stated earlier, the majority of CGs had little to no knowledge about hospice services prior to its introduction by the physicians. As previously stated, discussions with hospice personnel were the primary resource of information for the CGs. Most of the CGs had multiple conversations with the hospice personnel. Two CGs reported that after speaking with the hospice personnel, they used the internet to conduct further research on hospice and the services provided. One of the two CGs also reported using the internet to look up reviews of the hospice agencies that were presented to them as possible choices. Two CGs reported information they received from family and friends who had previously used hospice as another resource for information gathering in the decision-making process. Similarly, Noh (2014) found that 50% of terminally ill AA participants got their information from hospice providers, and 20% gathered information through internet sources.

Although family and friends were not primary sources of information in the current study, the family as a support resource was manifested in different ways. First as a decisional resource, all CGs reported a family discussion about hospice as an option. For many, a consensus was reached among family members before the decision was made to use hospice. Second, for families who chose home hospice, family and friends were a source of support in the physical care of their loved ones. The 24-hour need for assistance with activities of daily living for their loved ones was not met by hospice care. Therefore, CGs relied on other family members to bridge the gap in care and provide support. Previous literature supports a family-centered culture of healthcare and EOL decision making among AA families, and family support in the care of a loved one at home (Conner & Chase, 2014; Noh & Schroepfer, 2015; Raleigh, Robinson, Marold, & Jamison, 2006; Yancu et al., 2015). Family support in the AA community included friends and members of the wider community, such as their church community (Bullock, 2011; Campbell et al., 2010). In the current study, most CGs primarily described involving immediate relatives, such as siblings and adult children.

Research Subquestion 4

> What is the role of the African American family CG in the decision-making process to use hospice services?

For most family CGs, their role was that of primary decision maker. While a few CGs reported that their decision-making role was official because their loved ones had appointed them as their healthcare durable power of attorney, most reported an informal role. The informal decision-maker role either occurred early in their loved ones' illness or as a role assumed even before the illness, as a part of their family structure. In addition to making the initial decision to use hospice services, CGs also made the decision about the hospice agency that would be used and any decisions surrounding the coordination of care for their loved ones. AA family members often assume the formal or informal decision-making role at the EOL (Conner & Chase, 2014; Huang et al., 2012; Noh & Schroepfer, 2015). The decision-making role often is broad and involves decisions related to finances, coordination of care, treatment, and discontinuation of life sustaining treatment (Conner & Chase, 2014).

Research Subquestion 5

> What theoretical model explains the decision-making process of African American family caregivers' decision to use hospice services for their loved one?

The theoretical model developed from this study is visually presented in Figure 6. The model shows the introduction of the EOL condition of their loved one, followed by realizing the prognosis, and subsequently deciding to accept hospice care. At this point, decision making included selecting the appropriate service that would meet the needs of the patient, the CG, and family.

Comparison of Propositions to Evidence

Propositions were developed from the conceptual model and provided general information about the relationships among the model concepts generated from this study. The following section provides an interpretation of the propositions that emerged from this grounded theory study, with a comparison to existing research.

Propositions 1, 3, 4

- Realizing the EOL is at the core of the CGs' decision to use hospice services.
- CGs' understanding and accepting the end of life of their loved one is initiated by physician communication, patient comfort, disease progression, or declining condition.
- CGs' decision to accept and use hospice services is dependent on understanding and accepting the end of life of their loved one**.**

These three propositions are discussed together because they address the core concept of the conceptual model. These propositions are consistent with the subject of the first research subquestion addressed earlier. The evidence clearly supports the concept that realizing the EOL or the terminality of their loved ones' condition is at the core of the CGs' decision making, and supports the factors that led to this understanding (Lewis, 2014; Meeker et al., 2014; Waldrop et al., 2005).

Waldrop et al. (2005) explored family caregiving at the EOL and found that comprehension of terminality was a central theme that propelled CGs to final decision making for their loved one. Comprehension of terminality was explained as the realization that their loved one was dying (Waldrop et al., 2005). Lewis (2014) explored CGs' experiences when seeking hospice care for a loved one with dementia and described the EOL realization as reaching a boiling point, resulting in a change in mentality for CGs (Lewis, 2014). This boiling point was described as the point at which CGs decided that pursuing life prolonging care was no longer beneficial for their loved ones (Lewis, 2014). In yet another study that explored patients with advanced illness and their CGs' response to healthcare needs and decision making, Meeker et al. (2014) named *settling* as a significant emerging theme. Settling was described as the phase in which patients and their CGs settled into comfort-focused care and moved away from curative treatment (Meeker et al., 2014). The current study is aligned with these studies in the concept of the realization of the EOL being at the core of CGs' shift in focus to comfort care and hence hospice decision making.

The factors initiating or precipitating the realization of the EOL in the current study are also similar to previous evidence. The Waldrop et al. (2005) study found that receiving and understanding information about their loved one's diagnosis, prognosis, and progression of illness, and observing the progression of the illness in the patient's physical, behavioral, and cognitive changes were precipitating factors in the comprehension of terminality. Meeker et al. (2014) found that the receipt of clear, concise information from HCP about the patients' condition initiated the move to comfort focused care, and that receiving clear information fostered trust of the HCP.

The evidence also indicates that this concept is not only relevant to an African American or Black study population. In the Meeker et al. (2014) study, which described participants settling into the phase where their focus changed to comfort-focused care, 18% of participants were Black and 82% were White. Waldrop et al. (2005) found comprehension of terminality was the central theme in changing the focus of CGs to that of EOL decision making with 7% of participants AA, 92% Caucasian, and 1% Hispanic. Lewis (2014) described the realization of EOL also as a central theme termed reaching the boiling point, but did not specify the participants' race or ethnicity. The generality of the realization of EOL must be considered by HCP while working with AA families in this phase of their loved ones' illness.

Glaser and Strauss (1965), originators of the grounded theory methodology, conducted research on death and dying. Glaser and Strauss outlined a phase of dying called the *nothing more to do* phase, designated as the time when a patient no longer has a chance to recover, and death will occur at a known or unknown time. Glaser and Strauss posited that the nothing more to do phase signified the point where the goal of care for the patient changes to comfort instead of recovery; there can be a closed awareness or an open awareness of the change in the goals of care for this patient. An open awareness means that all involved, HCP and family, are aware of the change in the goal of care from recovery to comfort care (Glaser & Strauss, 1965). The current study findings illustrated an open awareness of the nothing more to do phase in the dying process, and the goal of care changed to comfort care. In this study, CGs began to move toward the new goal of care when they made the decision to use hospice services.

Proposition 2

Hospice as an option is initiated primarily by physician communication**.**

Physician communication of the hospice option is addressed in the answer to Research Subquestion 3. The majority of CGs in this study reported that the introduction of hospice as the next step in their loved ones' care came from the physician. Presentation of this information by the physician was received well by the majority of

CGs and the communication between CGs and physicians became a facilitator of the decision-making process. CGs trusted the expertise and knowledge of their physicians and hence could receive and accept the information.

While previous studies reported physician introduction of hospice services, many studies found that the mistrust of the hospice discussion between physicians and AA negatively affected the receipt of the hospice information (Ludke & Smucker, 2007; Pullis, 2011; Taxis, 2006). Mistrust of the healthcare system and physicians as a representative of that system is well documented in the literature (Bullock, 2011; Ludke & Smucker, 2007; Torke, Garas, Sexson, & Branch, 2005; Wicher & Meeker, 2012). The suggestion of hospice may be seen as a denial of treatment or the attempt to get rid of the AA patient (Taxis, 2006). This mistrust of the physician was not evident in the current study. The trust and comfort that the CGs reported could be attributed to the relationships developed through the course of the patients' illness, prior to the point when they were at the EOL.

The acceptance of the physician suggestion of hospice in this study may be explained by what Drought and Koenig (2002) referred to as an imbalance of power between patients and HCP, with HCP having more power. HCP control the scope and possibilities of treatment options available by what they present and the way in which it is presented, hence controlling the patients' choices (Drought & Koenig, 2002). AA patients, particularly, have reported a lack of power when communicating with their physicians (Peek et al., 2009). AA patients have also reported a lack of transparency and physician avoidance of information sharing (Lee et al., 2016; Peek et al., 2009).

In the current study, only one CG reported being given other treatment choices in addition to hospice care. Others were only given hospice as the option, given the condition of their loved one. However, CGs did not rely on the physician alone for evidence of their loved ones' prognoses. They also used their own observations of their loved ones' declining condition as they came to the EOL realization.

Proposition 5

Spirituality is used as a support for the decision to use hospice services.

In this study, CGs did not describe spirituality as directly influencing their decision to use hospice services. While all CGs reported having spiritual beliefs in God and religious affiliations, spirituality was used as a support or coping strategy during the decision-making process, and did not play an integral part in the process. CGs consistently reported that they leaned on God for support during the process, but were clear in the fact that their belief in God did not have a part in the actual decision to use hospice. This finding aligns with previous research that found that African Americans making EOL decisions found their spirituality or religion to be a source of comfort and support during the decision-making process (Campbell et al., 2010; Noh & Schroepfer, 2015; Yancu et al., 2015). Prayer, attending religious services, and reading and contemplating various religious passages are all used as sources of solace during times of illness and decision making for African Americans (Campbell et al., 2010). CGs in this study reported praying or talking to God as they were making the decision.

In contrast to this study's findings, there is strong evidence of spirituality and religion having a direct influence on hospice decision making, and was found to be a barrier to hospice use (Braun et al., 2008; Pullis, 2011; Wicher & Meeker, 2012).

African Americans believe that God is in control and decides when death will occur; therefore, it is incumbent upon HCP to continue with curative treatment until the time that God decides death (Braun et al., 2008; Campbell & Ash, 2007). This difference in findings is indicative of the variations in religious and spiritual beliefs and its influences on decision making in the AA community. HCP must consider these differences during the hospice decision-making process.

Proposition 6

> The interpersonal factor of their loved ones' comfort directly influences the CGs' decision to use hospice services.

Consistently, CGs reported wanting to make their loved ones comfortable and decrease their suffering. The desire for their loved ones' comfort became the focus for most CGs after the realization of EOL. This desire precipitated a shift in their focus of care from curative to comfort care and hence the decision to use hospice. Lewis (2014) found that participants had a change in mentality to comfort-focused care, where they preferred a comfortable death for their loved ones instead of aggressive treatment. The triggers for this change in focus were attributed to various reasons, such as the increasing of their loved ones' pain, the loss of dignity and joy of their loved ones because of the symptoms, or the torturous nature of further aggressive treatment (Lewis, 2014).

The Lewis study did not specify the race of the participants; however, Noh and Schroepfer (2015) found that AA patients wanted comfort care to manage their pain and other symptoms, instead of continuing with aggressive treatments. Of note also are many studies that found that AA participants viewed pain and suffering as a necessary part of their faith, and as a humbling experience necessary for Christians. This view was a barrier to hospice use because this was viewed as a justification for continued aggressive treatment (Braun et al., 2008; Huang et al., 2012; Rhodes, Batchelor, Lee, & Halm, 2015; Yancu et al., 2015). Spiritual or religious beliefs as it relates to suffering, pain, or aggressive treatment did not emerge in the current study. CGs viewed hospice as a means of making their loved ones comfortable during the dying process. The emergence of spirituality as a support, instead of a barrier as is shown in the literature, speaks to the varying spiritual and religious beliefs within the AA community that must be considered.

Proposition 7

> CGs' communication with immediate family members influences the realization of their loved ones' prognoses and the decision to use hospice.

CGs communicated with chosen family members regarding their loved ones' prognoses and the decision to use hospice. While many CGs were able to make independent decisions, they chose to include immediate family members, such as adult children, siblings, and parents. Previous evidence indicates that AAs value the input of both immediate and extended family members when making healthcare and EOL decisions (Campbell et al., 2010; Mazanec et al., 2010; Schubart et al., 2015). However, this concept is not completely supported in the current study. Many CGs did not include any extended family members and made the decision only to include their immediate family. This finding may be due to the level of education of the CGs in this study. Almost all participants had some college or were college graduates. This might account for their confidence in making the decision without input from extended family members.

Proposition 8

> CGs' hospice experience affects their decision to use hospice in the future for themselves or a loved one.

The majority of CGs in this study had positive experiences with hospice services. CGs were satisfied with all aspects of their loved ones' care including information received from hospice personnel before beginning care and while receiving care, coordination of care, and actual physical care received by their loved ones. Many CGs also reported follow-up contact from hospice personnel after their loved ones died. This positive experience is important. Several CGs reported that they would recommend hospice in the future for friends or relatives or would use it for themselves if necessary. This finding echoes the assertion by Conner and Chase (2014) that CG experiences are important because they are shared in the community, as it relates to the care received and the services available by hospice. The sharing of positive experiences can improve the knowledge level of those who may not be aware of hospice and the services offered.

Study Limitations and Strengths

There were several limitations to this study. The study was conducted in one geographic area with the 18 participants from the southeastern United States. There may be geographical differences related to the awareness of hospice and factors influencing decision making in the AA community. Fifteen of the 18 participants were female; hence, gender differences were not evident. Conner (2012) examined the relationship of demographic characteristics and other variables to predict hospice use among Blacks and found gender differences. Males were more likely to use hospice (Conner, 2012).

In qualitative research, the researcher is the vehicle for data collection and analysis. The researcher brings her own individual beliefs, experiences, and values that can create bias in interpretation. This researcher employed the strategy of bracketing to combat this issue; however, some bias may still have existed. Because the topic of death and dying is of a sensitive nature, some participants may have had selective recall of especially painful events during the interview, not revealing the full scope of the decision-making process and its influences.

The study also had several strengths. The study used qualitative methodology. Data collection was conducted using individual interviews with broad open-ended questions that allowed participants to describe their decision-making process about hospice as they recalled it. The study also used a grounded theory method that employs an established rigorous approach to the interpretation of interview data. The participants in this study also represented a variety of family CGs, including adult children and grandchildren, siblings, spouses, and other extended family members. This gives a broader perspective on the decision-making process of AAs surrounding hospice care.

Recommendations for Future Research

Several potential areas of research were identified from the findings of this study.

- Understanding the hospice decision-making process of AA patients who choose hospice care can illuminate areas of similarities and differences to inform interventions that can improve EOL decision making for AA population.
- Physician communication emerged as a facilitating factor in this study; therefore, further exploration of the types and content of effective physician

communication on hospice use among AA families could lead to specific interventions for training, and preparing physicians for communication with AA families at the EOL. Teaching this content to other healthcare professionals, such as nurses, is also important because they can reinforce content and continue to answer patient and CG questions about hospice in an effective way.

- Realization of the EOL emerged as the core of the decision-making process; therefore, exploration of the experience or meaning of coming to this realization, can improve understanding of this phenomenon and improve the decision-making process of this population.
- The effect of the type and quality of the relationship between the CG and patient on the decision-making process to use hospice should be explored.

Implications for Practice

The model developed in this study to explain the decision-making process of these CGs can be used as a foundation to improve the EOL and hospice decision-making process for AA families. Practice implications should include the following:

- Increase involvement of nurses in the communication of hospice care services. Through the rapport and relationships that nurses develop with patients and families, they can be a source of information for patients as they make the hospice decision

- Strengthen physician communication and relationships prior to the EOL condition of the patient to make the EOL conversation easier for patients and family members.
- Educate families about their loved ones’ ongoing condition and prognoses. Consistent education and updates by the nurses about treatment and the patients’ condition can help families realize when their loved one is coming to the EOL and hence facilitate a shift in the focus to comfort care.
- Frame the conversation about hospice with families in the context of hospice as a treatment option instead of the withholding of curative care.
- Involve churches as a prime location for education about hospice care services and preparation for the EOL, because all CGs reported spiritual beliefs and religious involvement.

Conclusion

A conceptual model explaining African American CGs’ process of decision making for a loved one who used hospice care was developed. At the core of the model is the CGs realizing the EOL prognoses of their loved ones. CGs went through the process of realizing that their loved one was at the EOL before making the decision to use hospice services. Physician communication was integral to the decision-making process because physicians introduced the EOL prognoses and the hospice option to the CGs. Physicians’ positive communication and relationship with the CGs facilitated acceptance of the prognoses and the subsequent hospice decision. CGs were also prompted to make the hospice decision by the desire to make their loved ones comfortable, and their own observations of the patients’ decline and disease progression. The study also found that other factors directly influenced the decision to use hospice, such as CGs’ ability to meet the care needs of their loved ones and communication with immediate family members.

Once the decision was made to use hospice, CGs began the selection of a hospice care agency, which involved decisions about home or outpatient care. This was followed by the transfer and admission of the patient to hospice care. The study also showed that most CGs were satisfied with the care received and would use hospice again for a loved one or themselves, and would also recommend its use to others.

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APPENDIX A

AFRICAN AMERICAN HEALTHCARE DECISION MAKING MATRIX TABLES

QUALITIATIVE STUDIES

Author/title	Qualitative design	Purpose	Sample	Findings related to decision making	Decision-making theory
Hopp et al. (2014). Go to the hospital or stay at home? A qualitative study of expected hospital decision making among older AA with advanced heart failure.	Descriptive	To explore the perceptions of AAs with heart failure, and their caregivers, concerning hospitalization.	*n* = 35 AA patients ≥ 60yrs old with advanced heart failure *n* = 10 caregivers	Factors affecting decision for hospitalizations: Self-monitoring Avoiding death Availability of resources at home Challenges of hospital care Communication of patient and caregivers	None
Lee et al. (2016). Elucidating patient-perceived role of decision making among AA receiving lung cancer care through a county safety-net system.	Unspecified	To explore patient-perceived role in decision making related to active treatment and palliation among AA receiving lung cancer care through a county safety-net system.	*n* = 13 patient caregiver dyads	Factors influencing role in treatment decision making: Challenges to effective communication. Caregivers as advocate and facilitator. Lack of understanding of prognosis and outcomes. Clinicians making decisions.	

Author/title	Qualitative design	Purpose	Sample	Findings related to decision making	Decision-making theory
Peek et al. (2009). Barriers and facilitators to shared decision making among AA with diabetes.	Phenomenology	To explore the barriers and facilitators of shared decision making among AA with diabetes.	*n* = 51 AAs	Barriers and facilitators: Patient/physician power imbalance exacerbated by race. Patient factors of health literacy, trust, family experiences, fear/denial, and self-efficacy. Physician factors of information sharing and patient education, validation of health concerns, medical knowledge and technical skills, accessibility and availability, interpersonal skills	None
Peek et al. (2013). Patient trust in physicians and shared decision making (SDM) among AA with diabetes.	Phenomenology	To explore patient trust in physicians and its relationship to SDM among AA with diabetes.	*n* = 51 AAs	AA race of patients seen as negatively influencing physician patient interpersonal interactions and influencing patient trust. Trust in medical & technical competence influenced by history of unethical experimentation with AA and an overall mistrust of healthcare. SDM facilitated patient trust but was also seen as a barrier due to physician implicit racial bias.	Constructs from Charles' SDM Model, theory of planned behavior, and the ecological model were used to frame the study. Authors created new conceptual model from findings where race & culture affected patient trust and SDM and Patient trust affected SDM

Author/title	Qualitative design	Purpose	Sample	Findings related to decision making	Decision-making theory
Rubin et al. (2013). "Use what God has given me": Difference and disparity in breast reconstruction.	Grounded Theory analysis	To develop a patient-centered understanding of reconstruction decisions based on the experiences of a diverse sample of AA women	*n* = 27 AA women who underwent mastectomies for breast cancer	Reasons for not having breast reconstruction: Implants and medical mistrust Body ethics Spirituality Reasons for electing breast reconstruction: Feeling normal Age Appearance SES and insurance coverage	None
Schubart et al. (2014) Breast cancer surgery decision making and AA women	Interpretive Descriptive	To identify key issues faced by AA women regarding breast cancer treatment decisions.	*n* = 14 AA women who have had breast cancer surgery	Issues affecting treatment decisions: Fear and worry Information sources and knowledge about breast cancer Support systems	None
Sheppard et al. (2010). The role of patient-provider communication for black women making decisions about breast cancer treatment.	Descriptive	To examine socio-cultural factors important to black women's diagnosis and treatment decisions; and healthcare-related factors that influenced treatment decisions.	*n* = 49 Black/AA women with stage 0-III breast cancer, ≤ 10 months postsurgery, adherence to treatment	Patient provider communication was the most influential factor on treatment decisions. Other factors with some influence were family relationships, spiritual and religious beliefs, trust of provider, and trust in the efficacy of treatments.	Bastian's adherence model of health behavior was used to frame the study.
Waite (2008). Perceptions of treatment for depression among underserved AA women.	Descriptive	To explore the perceptions and experience of AA women regarding depression treatment; and the factors that affect the perceptions and experience of this cohort.	*n* = 36 AA women diagnosed with depression in past year	Factors affecting treatment decisions were: Readiness for treatment – cognitive and behavioral issues; Negative judgment –from friends and family; Mistrust of the healthcare system – treatment regimen & doctors; Value of complementary and alternative therapy – holistic non-traditional treatment	None

Quantitative Studies

Author/title	Qualitative design	Purpose	Sample	Findings related to decision making	Decision-making theory
Harralson (2007). Factors influencing delay in seeking treatment for acute ischemic symptoms among lower income, urban women	Mixed methods	To examine factors that influenced the decision to seek emergency medical attention for acute myocardial infarction symptoms among women in a predominantly AA patient population.	*n* = 48 women 5 days following an acute ischemic event *n* = 32 AAs, 14 Whites, 2 Hispanics	88% of women talked to family or friends including church members, before making decision to go to hospital. 47% stated that someone helped them decide to get help Logistic regression showed that ethnicity did not increase the odds of delay of treatment	Self-regulatory model used to frame interviews
Palmer et al. (2012). AA prostate cancer survivors' treatment decision-making and quality of life.	Secondary data analysis, cross-sectional, case control	To examine AA prostate cancer survivors' involvement in treatment decision-making and examine the association between treatment decision making and quality of life.	*n* = 181 AA men diagnosed with prostate cancer within the last 6 months.	42% preferred making final decisions after considering MD's opinion; 39% preferred shared responsibility with MD; 14% preferred MD making decisions Top 3 information gathering sources for decision making were physicians, books & magazines, and family and friends Top 3 reasons for choosing treatment was best chance for cure, doctors' recommendation, and fewer side effects Patients whose MD made the final decision about treatment had better prostate cancer specific quality of life	None

APPENDIX B

AFRICAN AMERICAN DECISION MAKING SURROUNDING PALLIATIVE/HOSPICE CARE

QUALITATIVE STUDIES

Author/title	Qualitative design	Purpose	Sample	Findings related to decision making	Decision-making theory
Braun et al. (2008). Voices of AA, Caucasian and Hispanic Surrogates on the Burdens of End of Life (EOL) Decision Making	Unspecified	To describe the self-reported experience of AA, Caucasian, and Hispanic surrogate decision makers of seriously ill patients and to examine the relationship of race, ethnicity, and culture to that experience.	*n* = 44, 15 AAs, 14 Hispanics, 14 Caucasians	Burden of decision making • Personal; physical; financial; family; clinical Factors that affect the burden of decision making • Doctor-patient communication; time; trust; organizational factors; decision making vs reporting a decision; trial of intervention; faith/religion/spirituality; social support Race or ethnicity and decision making experiences among surrogates • Communication; religion/faith; trust; cultural beliefs	None
Bullock (2011). The influence of culture on end of life decision making.	Unspecified	To provide an overview of culturally-variant perspectives on EOL and palliative care. To offer reasons for differences in attitudes and behaviors in advance care planning. To discuss factors related to social support and family involvement in decision making	*n* = 102 Black, 100 White	Black participants valued collectivism, interdependence, interconnectedness, and present orientation. Blacks viewed hospice care as giving up while Whites viewed it as symptom management or comfort care Blacks believed in a higher power and miracles, those who believed in God did not believe in hospice care since it hastened death; whites viewed religion as a support in their EOL decision making Blacks reported more negative experiences with hospice and viewed it as giving up; Whites had more favorable comments	None

Author/title	Qualitative design	Purpose	Sample	Findings related to decision making	Decision-making theory
Campbell & Ash (2007). Keeping Faith	Descriptive-constant comparison data analysis	Study Questions How do AAs who have been diagnosed with a life limiting illness describe their experiences of living with their illness? What processes do they use to manage the experience of living with a life limiting illness?	*n* = 13 AAs	Belief that only God knew when they would die and he had the power to heal and create a miracle. God's knowledge superior to physicians. Being in hospice equates with denying a belief in God Paradox between God's plan and continuing aggressive treatment Tensions between belief in God and hospice philosophies	None
Campbell et al. (2010) Factors that influence end of life decision making in AAs with advance cancer.	Descriptive	Study questions: What individual, clinical, social factors influence AAs who have been diagnosed with a life limiting illness to choose hospice or other options for EOL care?	*n* = 7 AAs with stage III or IV cancer	Factors influencing AA choice of hospice or other options: • Physician involvement in decision making • Family involvement in decision making • Quality of life • Spirituality • Communication about prognosis	None specifically named. Article states conceptual framework but just describes factors in the literature which might affect EOL decision making for AAs
Conner & Chase (2014). Decisions and caregiving: End of life among blacks from the perspective of informal caregivers and decision makers	Phenomenology	To describe: 1. Various informal support relationships and the caregiving and decision-making roles they are in 2. Dynamics of the caregiving/decision-making process 3. Beliefs and values about EOL care among blacks who experience caregiving or health decision making for a seriously ill loved one.	*n* = 53 informal caregivers/decision makers	Decision making roles of caregivers: Physical care; financial management; coordination of care; treatment decisions including EOL care; placement; funeral arrangements Caregiving and decision making are based on past relationship roles Caregiver feelings of fear, anger, hurt, and love associated with decision making roles Validated role of family members in decision making in Black families	Andersen's behavioral model of health services use Andersen's concepts of family influence, belief and values, process of medical care, were supported

Author/title	Qualitative design	Purpose	*Sample*	Findings related to decision making	Decision-making theory
Johnson et al. (2016). The impact of faith beliefs on perceptions of end of life care and decision making among AA church members.	Unspecified	To understand the cultural and spiritual perspectives that influence decisions about palliative care and hospice among AA church members who visit and support persons with life limiting illnesses.	*n* = 51 AA adults who visit and support persons with life limiting illnesses	Influence of faith on EOL decision making • Faith provides peace, calmness, acceptance, less fear of death, strength, endurance, & less suffering Emotional burden of decision making • Many emotional responses experienced by patient & family such as fear, denial, grief, loss. Family dynamics, effect on decision making • Pre-existing family dynamics, conflicts r/t denial of pending death, differing faith beliefs, decision-making authority Facts and myths about palliative & hospice care • Many unfamiliar with terms palliative and hospice • Familiar=positive views; unfamiliar=negative views Communication • Majority reported unsatisfactory communication with healthcare personnel	none
Noh & Schroepfer (2015). Terminally ill AA elders' access to and use of hospice care.	Unspecified	To use Andersen's behavioral model for vulnerable populations to guide exploration: 1. The structural barriers terminally ill AA elders face when seeking access to hospice care as well as the strategies used to overcome then 2. The reasons terminally ill AA elders who have accessed hospice care chose to use it.	*n* = 28 AAs, >= 50 yrs old currently receiving hospice care	Structural barriers: Income, no impact Health insurance, no impact Location of agency, no role Administrative procedures, some inaccurate information, and misconceptions. Reasons for hospice use: Religion • Provided by God • Allows for spiritual/religious practices • Reliance on God for decision making Family-centered culture • Family centered and support of decision making • Some lack of family support for decisions Information source • Opposition to aggressive treatment • Perceived health decline • Knowledge of terminal condition	Andersen's behavioral model for vulnerable populations Model partially supported

Author/title	Qualitative design	Purpose	*Sample*	Findings related to decision making	Decision-making theory
Pullis (2011). Perceptions of hospice care among AAs.	Unspecified	To examine the perceptions of hospice care among AAs.	*n* = 41 AAs	Positive perception of hospice; would consider hospice at EOL Accessed information about hospice through doctors, internet, family & community members but reported mistrust for doctors Poor knowledge of hospice and services offered even after reporting familiarity with hospice	none
Taxis (2007). Attitudes, values and questions of AAs regarding participation in hospice programs	Unspecified	• What are the perceptions of AA regarding the philosophy, services, support, and accessibility of hospice programs? • What are the cultural values associated with EOL and how do these interface with the philosophical stance of hospice programs?	*n* = 28 AAs	3 main barriers to hospice participation: 1) a lack of information about hospice 2) cultural and 3) institutional barriers Sub-themes: 1)caring for loved ones at home 2) religion & spiritual practices 3) mistrust of the healthcare system and providers 4) respect from healthcare providers	None
Torke et al. (2008). Medical care at the end of life: views of AA patients in an urban hospital	Unspecified	To characterize the views of seriously ill AA patients toward EOL care	*n* = 23 AAs	Major themes: Desire for care, discussions about advance care planning Sub-themes • let me die • hope for a cure • relief of pain and suffering • in God's hands • limited role of doctor • family would make decisions • awareness of advance planning • timing of communication	none
Yancu et al. (2014). Accepting transitions: AAs discuss end of life	Unspecified	To explore AA attitudes toward dying and death among AA adults	*n* = 43 AA adults	1. Death as a difficult topic to discuss 2. Concept of a good death 3. Timing of conversations about dying 4. Support & assistance 5. When is hospice and palliative care a viable option 6. Conceptions about hospice 7. Transitions – curative to comfort care	none

Quantitative Studies

Author/title	Qualitative design	Purpose	Sample	Findings related to decision making	Decision-making theory
Conner (2012). Predictive factors of hospice use among blacks: applying Andersen's Behavioral Model	Descriptive correlational	To use the behavioral model of health service use to test the significance of demographics, beliefs and values, spirituality, social structure, and social relationships in predicting hospice use among blacks.	*n* = 104 Black adults	Gender, religious affiliation and presence of a caregiver as significant predictors of hospice use	Andersen's behavioral model of health services use. Concepts tested were supported Predisposing characteristics of demographics and enabling factors predictive of hospice use
Johnson et al. (2008). What explains racial differences in the use of advance directive and attitudes toward hospice care	Cross-sectional survey	To determine whether differences between older AA (AA) and White adults in the use of advance directives and attitudes toward hospice care were explained by differences in cultural beliefs and values.	*n* = 110 AAs *n* = 95 Whites	AAs less likely than Whites to have living wills or durable power of attorney (36% vs 67%) AA greater preference for life sustaining treatment; less comfort discussing death; greater distrust for healthcare system; spiritual beliefs conflicting with goals of palliative or hospice care; less favorable attitudes towards hospice care	None
Ludke & Smucker (2007). Racial differences in the willingness to use hospice services	Cross-sectional exploratory	To examine whether racial differences exist in the willingness to use hospice services in the future among black and white adults and potential factors that might contribute to the differences	*n* = 220 AAs *n* = 253 Whites	Whites more likely than blacks to consider use of hospice (89% vs 71%) Adjustment for demographic differences—blacks still less likely than whites to consider hospice even after M.D recommendation OR=0.38, 95% CI 0.11-0.61 Potential Factors of Influence Blacks rated preference for life sustaining treatment higher than Whites (49% vs 14.1%); prior exposure to hospice; satisfaction with prior hospice care; trust of physician	None

Author/title	Qualitative design	Purpose	*Sample*	Findings related to decision making	Decision-making theory
Rhodes et al. (2006). Access to hospice for AAs: Are they informed about the option of hospice?	Cross-sectional retrospective	To examine the use of hospice among AAs and whether lack of being informed represents a potential barrier. To examine characteristics of AAs who were informed about hospice services.	*n* = 111 informants of AA decedents	54% not informed about hospice; 30% chose to enroll in hospice; 9% informed about hospice but did not enroll; 47% unaware of whether decedents were informed about hospice; 1% unaware of hospice enrollment status of decedent Factors of gender, insurance, level of education, living status, or expectation of death not significantly associated with being informed about hospice	none
Zhang et al. (2011). Ethnic differences in the caregiver's attitudes and preferences about the treatment and care of advanced lung cancer patients.	Quantitative	To assess racial differences in the attitudes and preferences about cancer treatment and care between AA and White caregivers after controlling for demographic and socioeconomic factors	*n* = 173 Whites *n* = 26 AAs	AA caregivers more likely than Whites to report treatment as a goal to cure cancer (p = .03); hospice is a place to die (p = .01); hospice means hopelessness (p = .01); hospice is outside the home (p = .01).	none

APPENDIX C

INTERVIEW GUIDE

Introduction and Informed Consent

When the participant arrives, she/he will be given a demographic form to complete. The student Principal Investigator (PI) will then briefly describe the purpose of the interview emphasizing the following points:

"You have been invited to participate in a one-on-one interview about the decision to use hospice services in the African American community. Please share your personal views and experiences as it will help us better understand the African American family caregiver's decision making and experiences with the use of hospice services for a loved one. This information can be used to develop more culturally specific end of life care programs for African Americans. Your participation is voluntary and you may withdraw at any point during the study."

Next informed consent will be obtained. Participants will be asked to follow along as the consent form is read aloud. After reading the form, the following points will be emphasized:

"*I will be tape recording the interview so that I can accurately capture your comments. Only members of the research team will have access to the taped recordings. If you are uncomfortable with being recorded, please say so, and you will not be recorded. The recording will be kept in a secure area in the investigator's office. All identifying information will be removed before the tape is transcribed. Once the recording is transcribed it will be destroyed. Your name will not be used in any reports of the findings."*

Participants will then be asked if she/he has any questions. After the questions have been answered, the participant will be asked to sign one copy of the consent form and return it to the student PI. Each participant will be allowed to keep the second copy of the consent form for his/her personal records.
The student PI will then describe what is expected of the participant in terms of the interview process.

"*Please speak up so that your comments are captured by the recorder. Please say exactly what you think and do not worry about what I think. There is no right or wrong response. Your ideas and experiences are important."*

Introduction of Interview Questions/Topics

The student PI will introduce each question and explore it thoroughly using necessary prompts before moving on to another question. Questions are to be addressed in the following order:

1. Tell me what you knew, if anything, about hospice before your family member got sick

   Possible follow up if not addressed:

   If someone you know used hospice tell me what you know about their experience.

2. Please tell me about the decision to use hospice services for your loved one.

   Possible follow up if not addressed:

   How was hospice for your loved one introduced to you?

   When did the decision-making process to use hospice begin?

   Describe what influenced the decision (knowledge about disease, knowledge about hospice, living conditions, change in symptoms, religious or spiritual beliefs, and communication with healthcare personnel).

Did someone around you influence your decision (family, friends, church members, healthcare personnel) and if so how?

Did you seek any help to a make the decision (healthcare personnel, community, internet, family, church members, pastor/spiritual leader)?

3. Other than people, tell me about other considerations that influenced the decision to use hospice (beliefs about the healthcare system, finances, location of hospice facility, ability to care for loved one at home)
4. Tell me if the relationship with your loved one’s physician influenced your decision and if so how?

   Possible follow up if not addressed:

   Can you describe the discussion you had with the physician about the use of hospice for your loved one?
5. Tell me about the discussion you had with other family members, if any, about the decision to use hospice.
6. Describe what led to the final decision to use hospice for your loved one.

   Possible follow up if not addressed:

   When was the final decision to use hospice made?
7. Describe your emotions when you made the final decision to use hospice.
8. Please tell me about your experiences with hospice services

   Possible follow up if not addressed:

   What were/are you satisfied with about your experience? (Coordination of care, communication with healthcare personnel, access/availability/convenience, and comfort of loved one)

   What are/were you dissatisfied with about your experience?
9. What have those around you (family, friends, and church members) said about your decision?
10. As you look back at the process what most facilitated your decision and what most hindered your decision to use hospice services for your loved one, and what would you do differently?
11. Is there anything else you would like to tell me about that we have not discussed?

APPENDIX D

DEMOGRAPHIC DATA FORM

1. Do you identify as African American/Black?
    - Yes_________
    - No ____________
2. What is your gender?
    - Male _________
    - Female _______
3. What is your age? ____________
4. What is your level of education?

   High school _________

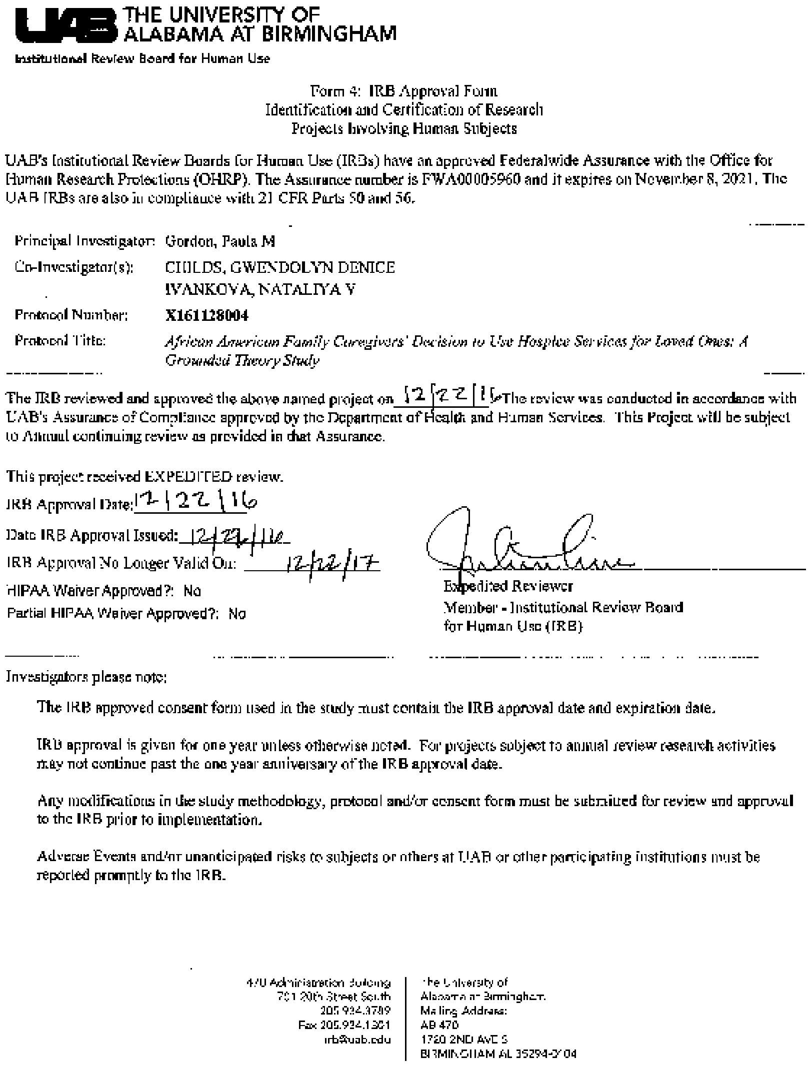
   Some College ________

   College graduate_______

   Other__________
5. What is your relationship to the hospice patient? _________
6. What is your religious affiliation? ________
7. What is/was the diagnosis of your loved one? __________
8. How long has/was your loved one receiving hospice care? ____________

APPENDIX E

IRB APPROVAL TO CONDUCT STUDY



THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

Institutional Review Board for Human Use

Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on November 8, 2021. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator:	Gordon, Paula M
Co-Investigator(s):	CHILDS, GWENDOLYN DENICE IVANKOVA, NATALIYA V
Protocol Number:	**X161128004**
Protocol Title:	*African American Family Caregivers' Decision to Use Hospice Services for Loved Ones: A Grounded Theory Study*

The IRB reviewed and approved the above named project on 12/22/16. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 12/22/16

Date IRB Approval Issued: 12/22/16

IRB Approval No Longer Valid On: 12/22/17

HIPAA Waiver Approved?: No

Partial HIPAA Waiver Approved?: No

Expedited Reviewer
Member - Institutional Review Board
for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

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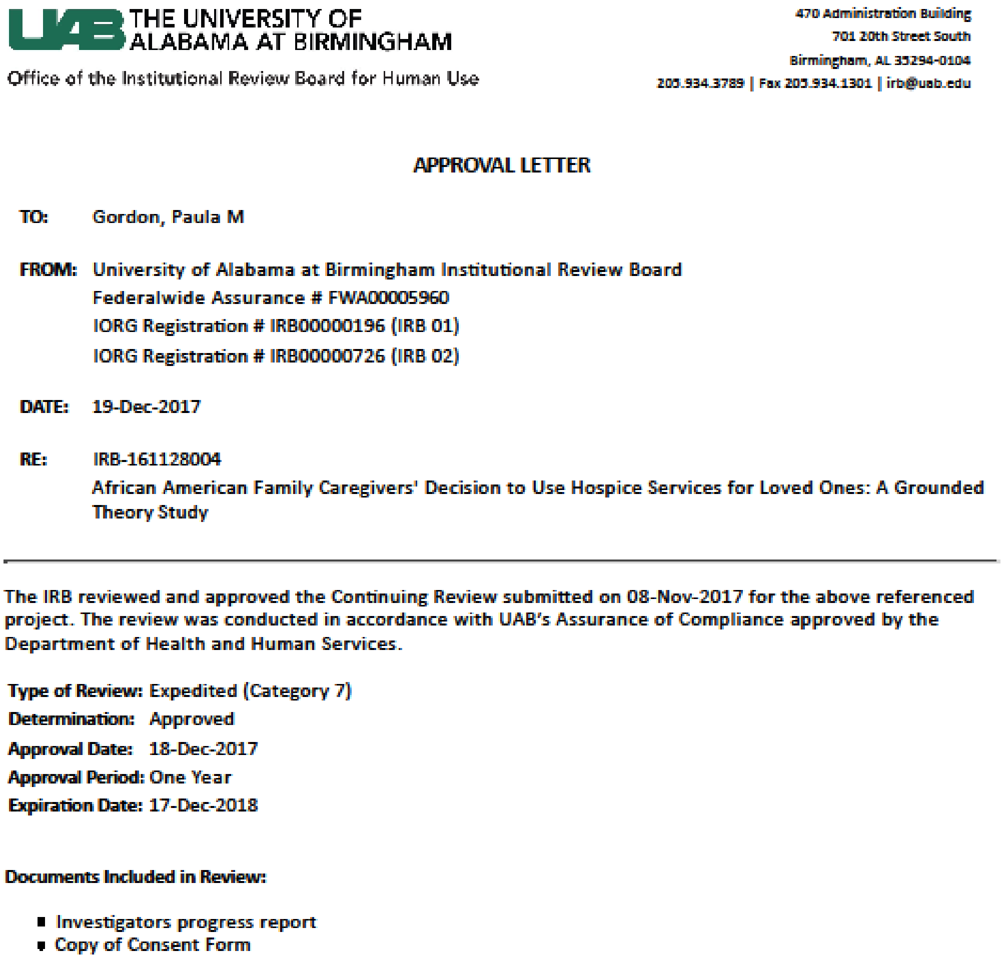

UAB THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
Office of the Institutional Review Board for Human Use

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APPROVAL LETTER

TO: Gordon, Paula M

FROM: University of Alabama at Birmingham Institutional Review Board
Federalwide Assurance # FWA00005960
IORG Registration # IRB00000196 (IRB 01)
IORG Registration # IRB00000726 (IRB 02)

DATE: 19-Dec-2017

RE: IRB-161128004
African American Family Caregivers' Decision to Use Hospice Services for Loved Ones: A Grounded Theory Study

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The IRB reviewed and approved the Continuing Review submitted on 08-Nov-2017 for the above referenced project. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services.

Type of Review: Expedited (Category 7)
Determination: Approved
Approval Date: 18-Dec-2017
Approval Period: One Year
Expiration Date: 17-Dec-2018

Documents Included in Review:

- Investigators progress report
- Copy of Consent Form