END-OF-LIFE DECISION-MAKING AMONG AFRICAN AMERICANS WITH

SERIOUS ILLNESS

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DEDICATION

This dissertation is dedicated to the loving memory of my Aunt Juanita "Dee Dee" Ray.

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I owe my family my undying love and gratitude for the support and encouragement they gave me during this academic journey. I am eternally grateful to my Mother, Jackie Howell, who has always been my biggest cheerleader. During the course of the PhD program, she was always a phone call away whenever I needed to hear "I love you" or "You can do it." I'm thankful for my Father, June Smith, for calling me "Doctor" years before I completed the program. The words he spoke years ago ring true today. I must thank my Aunt Barbara Ellis, whom I consider to be my "third mother." Aunt Barbara has supported me financially, as well as emotionally. Her weekly phone calls boosted my spirit and helped me believe that I could complete this degree. My Sister, Chevelle Howell, often called me to share a laugh and tell me how proud she was of me. I thank her for those laughs, because they kept me going.

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This dissertation study would have been impossible without the bereaved family members of Eskenazi Health's Palliative Care Program and Eastern Star Church who volunteered their time and life experiences for the sake of science. I am grateful to each person with whom I spoke. Some of the interviews were difficult to complete, because of participants' raw emotions. In spite of having to recall painful memories of decedents' deaths, the participants continued to share their and their loved ones' experiences.

My Aunt Juanita "Dee Dee" Ray is my inspiration for pursuing a doctorate. Her battle with lung cancer was the catalyst, which began my commitment to conduct end-of-life research. I promised my Aunt that I would pursue a PhD in order to conduct research to help other African Americans at the end-of-life avoid the hardships that she and our family endured as she neared death. My Aunt lives on in my heart, through my deliberate actions of generosity and kindness, through my words, through my writing, and through my career as an end-of-life researcher. The memories that I have of her make me smile, now; the tears are gone. Her legacy lives on through me and every person who is touched by the research that I conduct in her honor.

The poem below was written by one of the bereaved family members who participated in my dissertation research study. His words echo many of the feelings I had after my Aunt passed away. This poem states the necessity of end-of-life research.

Life after Death

Did we pay attention to the signs or down play the concern?

We were neither ready nor prepared, but what have we learned

Have to recognize the symbols or how to identify the cues

When to be proactive, not reactive and perhaps we could have kept them
by our side a little longer or they may have suffered a little less

You were not ready when it happened and a lesson lived is a lesson
learned

May the information you pass on may another be blessed

My father said to love your neighbor as you have loved yourself and life will be all the better while living and after death

There is one thing that we shall never lose the memories created and conceived to love and to honor means to obey and believe

Esther Renee Smith-Howell

END-OF-LIFE DECISION-MAKING AMONG AFRICAN AMERICANS WITH SERIOUS

ILLNESS

African Americans' tendency to choose life-prolonging treatments (LPT) over comfort focused care (CFC) at end-of-life is well documented but poorly understood. There is minimal knowledge about African American (AA) perceptions of decisions to continue or discontinue LPT. The purpose of this study was to examine AA family members' perceptions of factors that influenced end-of-life care decision-making for a relative who recently died from serious illness. A conceptual framework informed by the literature and the Ottawa Decision Support Framework was developed to guide this study. A retrospective, mixed methods design combined quantitative and qualitative descriptive approaches. Forty-nine bereaved AA family members of AA decedents with serious illness who died between 2 to 6 months prior to enrollment participated in a one-time telephone interview. Outcomes examined include end-of-life treatment decision, decision regret, and decisional conflict. Quantitative data were analyzed using descriptive statistics, independent-sample t-tests, Mann-Whitney U tests, chi-square tests, Spearman and Pearson correlations, and linear and logistic regressions. Qualitative data were analyzed using content analysis and qualitative descriptive methods. Family members' decisional conflict scores were negatively correlated with their quality of general communication (r_s = -.503, p = .000) and end-of-life communication scores (r_s = -.414, p = .003). There was a significant difference in decisional regret scores between family members of decedents who received CFC versus those who received LPT (p = .030). Family members' quality of general communication (p = .030) and end-of-life communication (p = .014) were significant predictors of family members' decisional conflict scores. Qualitative themes related to AA family members' experiences in end-of-life decision-making included understanding

feeling prepared or unprepared for death), relationships with healthcare providers (e.g., being shown care, distrust) and the quality of communication (e.g., being informed, openness, and inadequate information). Additional qualitative themes were related to perceptions of the decision to continue LPT (e.g., a lack of understanding, believe will benefit) or discontinue LPT (e.g., patient preferences, desire to prevent suffering). In conclusion, this study generated new knowledge of the factors that influenced AA bereaved family members' end-of-life decision-making for decedents with serious illnesses. Directions for future research were identified.

Susan E. Hickman, PhD, Co-Chair

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Background and Significance

Leading Causes of Death among African Americans

The medical technological advancements of the 21st century have changed the living and dying processes of Americans[1]. Individuals enjoy longer lifespans due to the eradication of communicable disease like polio and smallpox but then suffer age-related serious illnesses such as heart disease, stroke, and cancer[1-3]. The leading three causes of death for African Americans (AA) are heart diseases, cerebrovascular diseases (i.e., stroke), and cancer. African Americans suffer higher mortality rates than all other racial and ethnic groups from these conditions[4,5].

Comfort-focused Care may Benefit African Americans at End-of-life

Medical technological advancements offer myriad treatments for patients with serious illnesses, which complicates healthcare decision-making for these patients and their families[6]. Patients and family members must choose between different goals of care, which are determined based on patients' stages of disease, treatment options, and treatment outcomes. Goals of care include continuing life-prolonging treatment (LPT) or transitioning to comfort-focused care (CFC)[6]. Goals of care may change as patients' conditions change, which makes decision-making difficult for individuals with serious illnesses and their families[6]. When cure or life prolongation is unachievable, it is appropriate for patients, family members, and healthcare providers (HCP) to consider the option of CFC.

CFC is end-of-life (EOL) treatment with the goals of alleviating the patients' pain and suffering during the course of advanced illness, and preserving quality of life by foregoing life-prolonging measures. Hospice (See Table 1), a form of CFC, is recommended as the best available care for dying patients[7]. CFC is associated with several positive patient and family member outcomes[8]. Patients who choose CFC at

EOL have better symptom management, higher quality of life, and may even survive longer than patients who receive life-prolonging treatments (LPT)[9-11]. Caregivers of patients who choose CFC at EOL experience better quality of life, self-reported health, physical functioning, and mental health[9]. Additionally, caregivers of patients who receive CFC are better prepared for the patient's death and feel less regret than caregivers of patients who receive LPT at EOL[9-11].

African Americans Underuse Comfort-focused Care

Given the many benefits of CFC, it is likely that many AAs with serious illness could benefit from this type of EOL care. However, AAs tend to choose LPT instead, despite a small chance of cure[12-16]. Indeed, AAs represented only 8.5% of all hospice enrollees in 2011, even though they made up 13.6% of the total U.S. population[17,18]. AAs' tendency to choose LPT over CFC at EOL is well documented but poorly understood[12-16,19]. Furthermore, there remains a lack of knowledge about AA decisions to continue or discontinue LPT. Evidence suggests the factors that affect AA EOL decision-making are multifaceted. These factors include patient and family member characteristics, as well as the interaction between patients, family members, and HCPs. Communication is a critical component underlying these factors[1,20,21].

Importance of Communication Near the End-of-Life

To date, much of the research in palliative and EOL care has been conducted in cancer patient populations[1,22,23], including EOL communication research[24]. Since the breadth of our knowledge about palliative and EOL care is rooted in cancer care, it is reasonable to use existing empirical evidence related to cancer care to better understand palliative and EOL care in the context of other serious illnesses. Therefore, discussion regarding patient-family member-provider communication will focus on communication within the context of cancer care, since we have extensive knowledge pertaining to communication in this area of healthcare.

Communication within the context of cancer care is particularly complicated because patients and family members make decisions in the context of an illness that is both life threatening and, in some cases, curable[24]. Cancer care involves multiple HCPs from different medical specialties, disciplines, and multiple treatment decisions over time. Furthermore, cancer care often involves periods of uncertainty during and after treatment is completed, which is anxiety-provoking for patients and family members[24,25]. Effective patient-family member-provider communication can help patients and family members to receive bad news, cope with the emotions of a life-threatening illness, as well as understand and remember complicated information. Cancer patients and their family members must also be able to communicate with multiple HCPs effectively, understand prognosis, and manage uncertainty while sustaining hope. Furthermore, patients and family members must build trusting relationships with HCPs, make treatment decisions, and embrace health-promoting behaviors, all of which require effective patient-centered communication[24].

Patient-centered communication ideally involves eliciting and understanding patient and family member perspectives, as well as understanding patients and family members within their own psychosocial context[26]. Additionally, it requires patients, family members, and HCPs to attain a shared understanding of the problem and develop a treatment plan that is congruent with patient and family member values. Lastly, patient-centered communication requires HCPs to share authority and responsibility in healthcare with patients and family members by involving them in decisions as much as they desire[27].

Importance of Family Member Involvement. Communication is a central component of family member-centered care[28]. Family member-centered care is an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among HCPs, patients, and family members[29]. Family

members play an integral role in EOL decision-making[30], especially among AA patients[20,31-33]. AA patients prefer family member-centered care[20,31-33], where family members, caregivers, and friends (e.g., fictive kin) are actively involved in medical decision-making, participate in discussions about options, and give feedback about decisions[32-34].

Family member involvement in EOL treatment decisions is also important because dying patients discuss their EOL treatment preferences with family members more often than with their physicians.[35] Although evidence suggests that family members and physicians are inaccurate judges of patients' true EOL treatment preferences[36-38], family members tend to be more accurate than physicians[39]. In fact, one study found that as few as 3% of hospitalized elderly, seriously ill patients discussed their preferences regarding LPT with physicians while they were still able to express preferences, so family members may be the only source of information about patients' preferences[40,41]. Nearly half of all patients lose decision-making capacity prior to death because they are too ill[1,42,43]. Patients' inability to communicate their preferences at EOL makes family members particularly important in decision-making because EOL decisions, such as withholding LPT, are often collaborative family member-provider decisions[24,44,45].

Although communication is a key clinical skill for HCPs,[20,24] many patients and their family members continue to experience poor communication with HCPs about treatments at EOL[8,24,46]. Physicians' often fail to include family members in discussions about initiating CFC or discontinuing LPT, which can cause emotional distress for AA patients and family members[34]. Enhancing EOL discussions and improving understanding of EOL decision-making among patients with serious illnesses and their family members is essential to provide family member-centered care at EOL[34,47]. In order to develop interventions to improve AA decision-making at EOL, it is essential to

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better understand AA perceptions of the decisions to continue or discontinue LPT, as well as identify factors that contribute to EOL decision-making.

Purpose

The purpose of this study was to examine AA family members' perceptions of the factors that influenced EOL care decision-making for a relative who recently died with serious illness. A conceptual framework, informed by the literature and the Ottawa Decision Support Framework (ODSF), was developed to guide this study. Outcomes examined include EOL treatment decision, decision regret, and decisional conflict[48-52]. This study employed a mixed methods design, which included standardized surveys and a semi-structured interview with bereaved AA family members of decedents with serious illness who died between 2 to 6 months ago.

Specific Aims

Aim 1. Describe African American bereaved family members' perceptions of the decision to continue or discontinue life-prolonging treatment at the end-of-life.

Aim 2. Examine relationships among decedents' characteristics, bereaved family members' characteristics, quality of communication, end-of-life treatment decision, and decision outcomes.

> **Research question 2a.** What are the relationships between decedents' characteristics and: 1) quality of communication; 2) end-of-life treatment decision; and 3) decision outcomes?

> **Research question 2b.** What are the relationships between bereaved family members' characteristics and: 1) quality of communication; 2) end-of-life treatment decision; and 3) decision outcomes?

> **Research question 2c.** What are the relationships among family members' quality of communication and decision outcomes?

Research question 2d. Are there differences in decision outcomes by end-of-life treatment decision?

Research question 2e. Are there differences in quality of communication by end-of-life treatment decision?

Research question 2f. What antecedent and mediator variables in the conceptual model predict end-of-life treatment decision?

Research question 2g. What antecedent and mediator variables in the conceptual model predict decision outcomes?

Aim 3. Describe African American bereaved family members' experiences of end-of-life decision-making, quality of communication, and quality of relationships with healthcare providers.

Aim 4. Describe African American bereaved family members' perceptions of the decision to continue or discontinue life-prolonging treatment at the end-of-life.

In the remainder of this chapter, the investigator will discuss how the African American End-of-life Decision-making Conceptual Framework was developed. Discussion begins by describing the ODSF and then transitions to how the ODSF can be applied to EOL decision-making. Discussion continues with a description of how the ODSF can be used to bridge communication concepts to health behavior and psychology theories. Next, the investigator explains how the ODSF was used to develop the African American End-of-life Decision-making Conceptual Framework, and concludes the chapter with the key definitions of concepts of the study.

Ottawa Decision Support Framework

The ODSF is an evidence-based, interdisciplinary, conceptual framework that includes concepts from theories in general psychology, social psychology, decision analysis, decisional conflict, values, social support, and self-efficacy[25]. HCPs can use this framework to guide patients and family members in making health decisions[53].

HCPs can also use the ODSF to identify patient and family member decisional needs, which can be addressed by decision support interventions. This framework was developed mainly for decisions that are prompted by a new circumstance, diagnosis, or developmental transition. In addition, the ODSF is useful for decisions that require careful thought because of the uncertain and values-based nature of the benefits and risks of the decision(s). (See Figure 1: Ottawa Decision Support Framework).

Figure 1. Ottawa Decision Support Framework*

Ottawa Decision Support Framework

Assess Needs (Determinants of Decisions)

Perceptions of Decision
  Knowledge
  Expectations
  Values
  Decisional conflict
  Stage of decision making
  Predisposition towards options

Perceptions of Others
  Perceptions of others' opinions & practices
  Support
  Pressures
  Roles in decision making

Resources to Make Decision
  Personal
    Previous experience
    Self-confidence
    Motivation
    Skills in decision making
  External
    Support (information, advice, emotional,
      instrumental, financial, professional
      help) from social networks and agencies

Characteristics
  Client: age, sex, marital status, education,
    occupation, culture, locale, medical diag-
    nosis & duration, health status
  Practitioner: age, sex, education, specialty,
    culture, practice locale, experience,
    counseling style

Provide Decision Support

Provide access to information
  Health situation
  Options
  Outcomes
  Other's opinions and choices

Re-align expectations of outcomes

Clarify personal values for outcomes

Provide guidance/coaching in
  Steps in decision making
  Communicating with others
  Handling pressure
  Accessing support & resources

Evaluate

Decision making
  Reduced decisional conflict
  Improved knowledge
  Realistic expectations & norms
  Clear values
  Agreement between values & choice
  Implementation of chosen option
  Self-confidence and satisfaction with
    decision making

Outcomes of Decision
  Persistence with choice
  Improved quality of life
  Reduced distress
  Reduced regret
  Informed use of resources

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*Copied from O'Connor et al. (2002)[54]

Decision-making is a process in which patients and family members engage to choose between alternative courses of action[55]. According to the framework, HCPs can assist patients and family members in healthcare decision-making by: 1) assessing patient needs; 2) giving decision support; and 3) evaluating decision quality and outcomes (see Figure 2). First, HCPs must assess patients' and family members' decisional needs[25]. Decisional needs are patient and family member characteristics that are modifiable by decision support. Decisional needs are assessed to understand the context of decision-making and to identify which needs require tailored decision support. For instance, needs may be inadequate knowledge about the disease, unrealistic expectations for a cure, or unclear values regarding treatment. In addition to decisional needs, decision support can also be tailored to patient or family member characteristics such as age, race, and education level.

Once needs and characteristics are assessed, HCPs can then provide patients and family members with tailored decision support. The goal of the second step is to improve decision-making by implementing support based on patients' and family members' personal characteristics and decisional needs[55]. Examples of decision support include providing information about the health situation when patients and family members have inadequate knowledge, realigning expectations of outcomes by describing outcomes in detail, or clarifying patient and family member values[55]. In the final step, HCPs evaluate patient and family member decision-making and decision outcomes. The ODSF allows HCPs to evaluate decision quality and decision outcomes separately. The framework defines an optimal decision as one that is informed, congruent with patients' and family members' values, actualized, and results in patient and family member satisfaction with decision-making[55-57]. Decisions are based upon patient and family member values, which cannot be judged as right or wrong. Thus, a

patient and family member could make an optimal decision but still experience a bad outcome because of the unpredictable nature of clinical outcomes[55].

Ottawa Decision Support Framework, serious illness, and end-of-life. Difficult decisions arise more often at EOL than in earlier phases of most disease trajectories[24]. Patients at EOL and their family members must make complicated, values-based decisions (e.g., continuing or discontinuing LPT) that result in uncertain outcomes[58]. HCPs also face challenges as they provide care for these patients and their family members. HCPs must communicate clinical information, deliver bad news, respond to patient and family member emotions, handle patient and family member requests to use futile treatments, and manage patient and family member uncertainty[24,59,60].

A high-quality decision is one that is predicated on the patients' and family members' needs, values, and preferences[24]. However, making a high-quality decision is difficult because HCPs are often unaware of patients' and family members' needs, values, and preferences. In addition, patients and family members typically have not considered all treatment options prior to medical visits. Furthermore, patients, family members, and HCPs commonly hold different beliefs about health[24]. Given the difficulties in EOL decision-making, the ODSF can assist HCPs as they guide patients and family members toward a high-quality decision that meets their needs and values at EOL.

Ottawa Decision Support Framework, Communication Concepts, and Health Behavior and Psychology Theories. Communication literature calls for communication concepts to be integrated with theories of health behavior and health psychology in order to inform and explain the relationships between communication and healthcare outcomes[24]. When patients, family members, and HCPs interact, the communication exchange among them is an integral part of the interaction. Patient-

family member-provider communication impacts patient and family member healthcare outcomes[61]. Thus, patient-family member-provider interaction is one example in which communication relates to healthcare outcomes.

Integrating the concept of patient-centered communication and the ODSF bridges health behavior and psychology theories. The ODSF enables HCPs to evaluate decision outcomes (decision regret and decisional conflict), which are important health outcomes across the healthcare continuum. Patient-centered communication fits well with the ODSF because this framework is based on a patient- and family member-centered approach that acknowledges patient and family member characteristics and psychosocial contexts that influence decision-making[62]. Furthermore, the goals of the ODSF parallel the goals of patient-centered communication. Both the ODSF and patient-centered communication assist HCPs to provide care that is congruent with patient values, needs, and preferences, and allows patients to participate in healthcare decision-making[25,27].

African American End-of-life Decision-making Conceptual Framework

Using patient-centered communication and the ODSF, the investigator developed a framework to guide research on AA EOL decision-making. The investigator found no conceptual framework in the literature that could be easily adapted to guide research on AA decision-making at EOL; therefore, a novel framework was developed. Several concepts of the ODSF were relevant to this study and integrated into the African American End-of-life Decision-making Conceptual Framework, including family member characteristics and decision outcomes (decision regret and decisional conflict). The African American End-of-life Decision-making Conceptual Framework was used to explain the influences of decision-making for bereaved AA family members of decedents with serious illness (see Figure 2).

Factors associated with AA decision-making at EOL include the patient and family member characteristics of knowledge of disease, treatment options, and treatment outcomes; knowledge of EOL care options; mistrust in the healthcare system; religious values; cultural values; age; gender; income; education; and religious affiliation. Patient-family member-provider interaction also influences decision-making, including problematic patient-family member-provider relationships and communication. These variables may influence AAs' EOL treatment decisions to use CFC or LPT and their decision outcomes (decision regret and decisional conflict).

Figure 2. African American End-of-life Decision-making Conceptual Framework.

Antecedents Mediators Outcomes

Decedent and Family Member Characteristics
- Age
- Gender
- Income
- Education Level
- Relationship to Decedent (Family members only)
- Religious Affiliation
- Religious Values (Family members only)
- Cultural Values
- Medical Mistrust
- Knowledge of Disease Diagnosis, Treatment Options, Treatment Outcomes
- Knowledge of End-of-life Care Options

Decedent-Family Member-Provider Interaction
- Quality of Communication
  - General
  - End-of-life
- Relationship with Healthcare Team

End-of-life Treatment Decision

Decision Outcomes
- Decision Regret
- Decisional Conflict

Note: Variables in gray were assessed qualitatively. Variables in black were assessed quantitatively.

Definitions of Key Terms

There are several key terms used throughout this proposal. To ensure a clear understanding of these terms within the context of this research, terms are listed below as they appear in the conceptual framework beginning on the left side of the framework and ending on the right.

Table 1. Key Definitions

Key Term	Conceptual and Operational Definitions
Decedent and Family Member Characteristics	
Characteristics	***Conceptual definition:*** Social characteristics of participants.[57] ***Operational definition:*** **Quantitative:** Characteristics were assessed using participant self-report using an 11-item investigator-developed demographic survey. Data collected will include the decedent's and family member's age, gender, income, years of education, and religious affiliation. Bereaved family member's relationship to the decedent will also be assessed. Age was assessed using the open-ended questions: "How old are you?" and "How old was your family member when s/he passed away?" Gender of family members was assessed using the survey question "Are you male or female?" Gender of decedents was assessed using the survey question "Was your loved one male or female?" Income was assessed using the survey question: "Please stop me when I come to your total combined yearly household income before taxes. Is it?" Categorical response options ranging from 'less than $15,000' to 'more than $100,000' was read to each participant. Years of education was assessed using the question: "Please stop me when I come to the highest grade or year of school you finished. Is it?" Categorical response options ranging from 'no school or kindergarten' to 'completed graduate degree' were read to each participant. Participant's relationship to the decedent was assessed using the open-ended question: "Please stop me when I come to the phrase that best describes your relationship to the family member? Where you his or her?" Sample categorical

Key Term	Conceptual and Operational Definitions
	response options include, "Husband", "Wife", Daughter or Step-daughter", and "Son or Step-son."
	Religious affiliation was assessed using the open-ended question: "What is your religious affiliation?"
Religious Values	***Conceptual definition:*** Organized activities (e.g., attending a religious service), non-organized religious actions (e.g., personal religious actions) and internal religiousness that motivate behavior and decision-making.[63-65]
	Operational definition: Religious values was assessed using the following question from the semi-structured interview guide: "How did religious values influence your decision towards or against life-prolonging treatment or comfort-focused care?"
	Religious values was also assessed using the Beliefs and Values Scale[52]. The Beliefs and Values Scale measures strength of spiritual and religious beliefs. The 20-item scale assesses spiritual beliefs using a 5-point Likert-type scale, where 0 = strongly disagree and 4 = strongly agree. Higher scores indicate stronger spiritual beliefs.[52] Sample Beliefs and Values Scale items include: 1) "I am a spiritual person", 2) "I believe I have a spirit or soul that can survive my death", and 3) "I believe in a personal God."
Cultural Values	***Conceptual definition:*** Culture is "the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group." (p. 7)[66]
	Operational definition: **Qualitative:** Cultural values was assessed using the following question from the semi-structured interview guide: "Please describe what cultural values, if any, that were important to you and your loved one as you made decisions about your loved one's healthcare. By cultural values, I mean things that are important to you as an African American."
Medical Mistrust	***Conceptual definition:*** Distrust of the medical system and healthcare professionals generated specifically by racial difference between the patient and HCP who is from the majority racial group.[67]
	Operational definition: **Qualitative:** Medical mistrust was assessed using the following questions from the semi-structured interview guide:

Key Term	Conceptual and Operational Definitions
	"How did trust play a role in this [with the healthcare team] relationship?" and "Describe an instance where you felt you could not trust the healthcare team."
Knowledge	***Conceptual definition:*** Awareness of a health issue, options, and consequences[25]. ***Operational definition:*** <u>**Qualitative:**</u> Knowledge was assessed using the following questions from the semi-structured interview guide: 1) "How did you first learn about your loved one's medical diagnosis?" 2) "What did you know about this condition at the time he/she was diagnosed?" and 3) "Did this knowledge change over time?"

Decedent-Family Member-Provider Interaction

Quality of Communication	***Conceptual definition:*** Communication that stimulates patient and family member involvement, understanding, and promotes shared understanding of the medical problem and treatment that reflects patient and family member values and preference[26]. ***Operational definition:*** <u>**Qualitative:**</u> Quality of communication was assessed using the following questions from the semi-structured interview guide: "What was helpful to your communication with the healthcare team?" and "Describe situations where the communication could have been better." <u>**Quantitative:**</u> Quality of communication was also assessed using the Quality of Communication Scale. The Quality of Communication Scale is a 13-item scale with scoring from 0, "Poor" to 10, "Absolutely Perfect." The middle of the scale with the value of "5" indicates "Very Good." If the doctor or nurse cannot be rated because he or she did not do it, or if the participant does not know, the options of "The clinician didn't do this" or "I do not know" were also be available. The overall scale is comprised of two subscales including the general communication scale and end-of-life communication subscale.[68] Sample Quality of Communication Scale items include: 1) "How good was the healthcare team at using words that you understood?" 2) "How good was the healthcare team at looking you in the eye?", and 3) "How good was the healthcare team at talking about how long your loved one had to live?"

Key Term	Conceptual and Operational Definitions
Decedent-Family Member-Provider Relationship	***Conceptual definition:*** A relationship between a healthcare provider, patient, and family member[69]. **Operational definition:** <u>Qualitative:</u> Relationships was assessed using the following question from the semi-structured interview guide: "How would you describe your relationship with the healthcare team?"

End-of-life Treatment Decision

Life-prolonging Treatment	***Conceptual definition:*** Treatment that prolongs life without treating the primary medical condition[70]. ***Operational definition:*** <u>Quantitative:</u> Life-prolonging treatment was assessed using the following item: "In the last month of life, was the goal of your loved one's treatment focused on keeping him or her comfortable or more towards trying to cure to him or her of illness? For example, did the decedent receive comfort-focused care, such as hospice, or did they continue treatments to cure the illness?" Categorical response options include 'life-prolonging treatment' or 'comfort-focused care'.
Comfort-focused Care	***Conceptual definition:*** An approach to care with the goal of easing patients' pain and suffering during the course of advanced illness without the use of life-prolonging treatment. CFC care is care offered to those patients with advanced and life-threatening illness who may or may not be enrolled in a hospice or palliative care program, who have refused life-prolonging treatment, and who may be receiving care in a variety of settings, including a home, hospital, nursing home, long-term care facility, or hospice.[19,71-73] **Operational definition:** <u>Quantitative:</u> Comfort-focused care was assessed using the following item: "In the last month of life, was the goal of your loved one's treatment focused on keeping him or her comfortable or more towards trying to cure to him or her of illness? For example, did the decedent receive comfort-focused care, such as hospice, or did they continue treatments to cure the illness?" Categorical response options include 'life-prolonging treatment' or 'comfort-focused care'.

Decision Outcomes

Decision Regret	***Conceptual Definition:*** Distress or sorrow after a healthcare decision.[74]

Key Term	Conceptual and Operational Definitions
	Operational Definition: **Qualitative:** Decision regret was assessed using the following question from the semi-structured interview guide: If you could do it all over, what, if anything, would you do differently? **Quantitative:** Decision regret was also assessed using the Decision Regret Scale[48]. The 5-item scale assesses decision regret using a 5-point Likert scale, where 1 = *strongly agree* and 5 = *strongly disagree.* Higher scores indicate a higher level of regret. Sample Decision Regret Scale items include: 1) "The decision to stop (or continue) treatment was the right decision." 2) "I regret the choice about treatment that was made for my loved one's end-of-life care.", and 3) "I would choose the same treatment plan again if I had to do it over."
Decisional Conflict	**Conceptual Definition:** Uncertainty about decisions with several options that involve risk, loss, regret, and that threaten life values.[25] **Operational Definition:** **Quantitative:** Decisional conflict was assessed using the Decisional Conflict Scale.[50] The scale measures personal perceptions of: a) uncertainty in choosing options; b) amendable factors influencing uncertainty such as feeling uninformed, unclear about personal values, and unsupported in decision-making; and c) effective decision-making such as feeling the choice is informed, values-based, and likely to be implemented, as well as expressing satisfaction with the choice[50]. Decisional conflict was measured using a 10-item scale. Decisional conflict was assessed using questions with 3 response options, where *yes = 0, no = 4,* and *unsure = 2*[50]. Higher scores indicate higher decisional conflict. Sample Decisional Conflict Scale items include: 1) "Did you and your loved one know which treatment options were available to you?", 2) "Did you and your loved one know the benefits of each treatment option?", and 3) "Did you and your loved one know the risks and side effects of each treatment option?"

Summary

AAs are disproportionately affected by high mortality rates for several serious illnesses, and many AAs could benefit from CFC at EOL. However, AAs underuse CFC, despite the benefits that CFC offers. Numerous factors are associated with AA EOL

decision-making, including patient and family member characteristics and patient-family member-provider interaction.

Although evidence suggests that religion is a source of support for AAs, few investigators have explored whether religious values are associated with EOL decision-making[34]. This study will fill an important gap in the literature concerning the influence of religious values among AAs with serious illness at EOL. Research focusing on AAs with serious illness at EOL will also increase AA participation in medical research, particularly EOL research, which has historically been low[75-78]. Furthermore, this study will extend the current state-of-the-science in EOL care and nursing research, and address EOL research priorities identified by national healthcare and research organizations.

Because the study will examine decision-making from the perspective of the family member, valuable new knowledge will be generated, which ultimately will lead to interventions to support decision-making and enhance communication among AAs with serious illness, their families, and HCPs[34]. Lastly, the ODSF has not been applied in studies focused on ethnically diverse populations or bereaved family members. In fact, only three EOL studies have validated the use of the decisional conflict scale, and no studies have used Ottawa Decision Support scales with bereaved AA family members of AAs who died from serious illness. This study will extend knowledge related to the ODSF and decision support science by contributing findings from an ethnically diverse sample of bereaved AA family members of patients who faced life-limiting illnesses at EOL.

Chapter Two

Review of Literature

This chapter contains a review of the factors that influence African American (AA) end-of-life (EOL) decision-making as depicted in the African American End-of-life Decision-making Conceptual Framework (see Figure 2), which was developed to guide this study. The chapter begins with a discussion of palliative care, hospice care, and comfort-focused care (CFC) to define the terms that will be referenced throughout the chapter. This discussion will also briefly explain the type of palliative care that patients and family members received at Eskenazi Health's Palliative Care Program, a recruitment site for this study. Next, discussion will focus on patients' and family members' characteristics, and then transition to patient-family member-provider interaction factors. The chapter concludes with discussion of decision outcomes.

A mixture of interrelated factors affects AA EOL decision-making; these include patients' and family members' characteristics and patient-family member-provider interactions. AA patients' and family members' decision-making is affected by AA characteristics including cultural values[1,16,24,31,40,79-87], religious values[12,31,32,80,88,89], and mistrust of the healthcare system[14,16,83,87,90-98]. Other equally important factors include AA patients' and family members' limited knowledge about disease diagnosis, treatment options[97,99-101] , and EOL care options[16,97,98,102,103]. Furthermore, numerous studies have shown patient-family member-provider communication and relationships to be of crucial importance to decision-making and quality EOL care[7,8,46,104-108].

Types of Comfort-Focused Care

Hospice. EOL research has a lack of definitional clarity for several main concepts and terms, including palliative care, EOL, and hospice care[2,109]. Hospice and palliative care have been interchangeably used to refer to EOL care, though the conceptual meanings of these models of care are distinct[1].

The term 'hospice' has at least three different uses[1], referring to a site of care[1,19], an organization or program that provides medical and supportive services for dying patients (expected to live six months or less) and their family members[1,71,73], or an approach to care for dying patients (expected to live six months or less) based on clinical, social, and metaphysical, or spiritual values[1,19,109]. Hospice focuses on improving the quality of life for terminally ill patients and their family members, without curative treatment of illness[19,110]. Hospice care also precludes the use of intermediary care to treat chronic disease and thus alter the natural history of the disease course[109].

Palliative care. Palliative care is defined as, "an approach to care which seeks to improve the quality of life of patients and their family members facing problems associated with life-threatening illness through the prevention and relief of suffering by means of impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual[111]." This care serves as a comprehensive intermediate form of care for patients at EOL, as well as those who may not be facing EOL but could benefit from symptom relief[109]. In contrast to hospice care, palliative care may be implemented earlier in the disease trajectory, along with life prolonging-treatment (LPT)[109]. As a result, palliative care can be implemented prior to the point when hospice referral is appropriate[72,109].

Several models of palliative care exist by which patients and family members can receive EOL care, including via a solo practitioner, geographic, or full team model[112]. In the solo practitioner model, patients and family members receive care from a single physician or advanced nurse practitioner and are referred to other services, such as social work[112]. Patients receiving care via the geographic model are a part of an inpatient program, designated to a unit, and receive care from a team of healthcare providers (HCP), such as a physician, nurse, social worker, chaplain, and therapist[112]. The full team model approach to palliative care is a consultative service with a full team

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of healthcare providers (HCP), including a physician, nurse, and social worker. Team members refer patients to other services and discharge patients to appropriate settings[112]. The full team model approach to palliative care has several benefits, including exposing patients and family members to comprehensive medical expertise; providing patients and family members with care and services that are coordinated by several HCPs working in unison; and providing tailored care that encompasses physical, spiritual, and emotional care to meet patients' and family members' multidimensional needs[112]. The Eskenazi Palliative Program, a recruitment site for this study, uses the full team model approach to serve patients and family members with an interdisciplinary team of physicians, nurses, social workers, a spiritual advisor, and community volunteers.

Comfort-focused care. Hospice and palliative care both seek to ease patients' pain and suffering during the course of advanced illness while preserving adequate quality of life for patients and their family members[1,110] . The differences lie in the type of patients served (those dying verses those with advanced and life-threatening illness)[113]; the type of services offered (palliative non-curative care versus simultaneous curative and palliative care)[113]; and the point in time along the disease continuum when care is implemented (six-month prognosis versus any stage of advanced illness)[113].

For the sake of clarity, when this study refers to an approach of care with the goal of easing patients' pain and suffering during the course of advanced illness without the use of LPTs, the term "comfort-focused care" will be used. CFC is defined to include care offered to those patients with advanced and life-threatening illness who may or may not be enrolled in a hospice or palliative care program, who have refused LPTs, and who may be receiving care in a variety of settings, including a home, hospital, nursing home, long-term care facility, or hospice [19,71-73].

Patients' and Family Members' Characteristics

    Cultural values.

    Culture and communication. Quality EOL care is an outcome of strong patient-family member-provider relationships and clear communication that is based on patient and family member values [24,86,100,114]. Several factors can hinder communication and establishment of patient-family member-provider relationships during the EOL care process[32,79,115,116]. Of these factors, cultural differences between providers, patients, and family members are a key barrier[79,116]. Patient-family member-provider relationships and communication are made more complex by cultural differences[80,81], which are especially evident during EOL care interactions[85,86]. Acknowledging the influence of culture on people's views and behaviors may enhance communication and improve care for those patients who are from a different culture than that of the HCP[117].

    Culture is defined as "the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group" (p. 7)[66]. Culture permeates every aspect of life[117,118] and influences people's perceptions and experiences of life events including health, illness[118], death, dying, and EOL care[114,119-121]. Cultural beliefs and practices help patients and family members cope with fear, stress, and grief by supplying support and meaning to experiences[85] through religion[85,117,122], historical and social experiences[85], and information passed down from older generations to younger generations[85,123]. Evidence suggests that when patients' and family members' cultural values are unacknowledged, they receive unwanted and suboptimal care from HCPs who are from a different culture[12,82,84,114]. Despite this evidence, many providers are still unaware of cultural variations in patient and family member values[81,85,86].

    African American culture. Given the breadth of culture's influence and the clinical implications for patients' and family members' heath care outcomes, it is helpful

to use culture as the backdrop that leads the discussion of the factors that contribute to AA EOL decision-making. AAs are mainly the descendants of slaves[124] and the AA culture is the result of a fusion of west, central, and south African cultural traits (e.g., language, religion, family structure, and food customs[125]) and American-European cultural traits (e.g., English and Christianity[126]) that merged under slavery[126,127]. Present-day AA culture is distinct due to acculturation and oppression in American society[126,128,129]. Two major AA cultural traits that result from a history of injustice and discrimination in American society are the struggle for survival[130] and mistrust in the American healthcare system[131-134]. AAs' attitudes toward EOL care interventions (particularly for LPT), death, and dying may be due, in part, to cultural values[31,87,135-138]. To gain a better understanding of AA EOL decision-making, the discussion on cultural values will focus on three aspects of AA culture including religious values, struggle for survival, and medical mistrust[139-141].

   Religious values. Religion may be the best way to understand the individuals who belong to a particular culture[142] because religion influences individuals' emotions and behaviors[143,144], and serves as a lens through which they view and understand their reality[145,146]. Within AA communities, religion is a dominant influence that guides healthcare decision-making[147], especially at EOL[148]. AA culture and religion are intricately interwoven together because many facets of AA culture have religious roots that have been cultivated in the AA church[122,142,149].

   The AA church is a combination of churches from many denominations, including historically AA denominations (e.g., African Methodist Episcopal Zion Church) and American-European denominations (e.g., Church of Christ)[122]. Congregations within the AA church are comprised of majority or all AA members and have a culturally distinct African-influenced worship style (e.g., call-and-response sermons, shouting, spirited testimonies, singing spirituals, and using African rhythm). Additionally, churches within

the larger AA church support AA communities in several capacities including through political, financial, and educational programs[122,142,150,151].

Religion shapes African American culture and end-of-life decision-making. The AA church was created during slavery and was the single largest force shaping AA culture during enslavement and thereafter[122,136]. As the only significant social institution to emerge from slavery aside from the AA family, the AA church is a multifunctional symbolic center of the AA community[142,149,152]. Given the church's importance, naturally, the leaders of the church also serve as leaders in the AA community[153]. AA religious leaders have the unique and challenging task of fulfilling the spiritual, emotional, and communal needs of the AA community[122]. Hence, AAs have high expectations of religious leaders during illness, dying, and death[117]. Research suggests that AA beliefs about dying are strongly influenced by religious beliefs and practices[3,31,51], and AAs are most likely to seek pastoral help when making important decisions[148], including health decisions[154,155] associated with death[156]. Evidence shows that some AA pastors place high importance on the therapeutic use of religious practices such as prayer, faith healing, quoting scripture, and church attendance[157], and many AAs report using these religious practices to cope with symptoms, suffering, and to make sense of experiences during the dying process[137].

Because religion functions as a framework through which individuals find meaning and understanding in suffering and death[158,159], AAs may use religious values to navigate and cope with illness, suffering, and EOL[95,160]. In fact, evidence suggests that AA religious values guide decision-making[161] and may supersede professional medical recommendations at EOL[95]. Since AAs may be more likely to use religion to help guide decision-making, it is helpful to understand how specific religious values influence AA health behaviors[162,163].

Influence of specific religious values.

God's will. Some AAs strongly believe that God is concerned and actively involved in the lives of humans[160]. Studies show that some AAs believe that God's will is responsible for physical healing, life, and death[136]. Additionally, some AAs believe that God uses HCPs as tools to promote healing[164,165]. The belief in God's will and ability to use HCPs as instruments may be a powerful influence on patients' and family members' decisions to use LPT as opposed to CFC at EOL[160].

Advance directives. Evidence shows that AAs are less likely to have an advance directive compared to White Americans[166]. Belief in God's will may be a contributing factor to AAs' underuse of advance directives[90]. AA patients who are less likely to complete advance directives may believe that God's will, not human plans, determines whether an individual lives, or dies[136,166]. One study participant illustrated some AAs' views on advance care directives when she stated, "If one believes in God, why would you need or want to have choices about end-of-life care? You don't need a contract with anyone but God[167]."

Divine intervention and miracles. Some AAs strongly believe in God's power for divine intervention and miracles through prayer[95]. AAs often use prayer to cope with illness and medical problems[168-170], and are more likely to cite prayer as the most important factor in medication decisions than White Americans[171]. In fact, for some AA cancer survivors, prayer was the most helpful intervention, even superseding medicinal aids[165]. More often than White Americans, AAs report praying for healing of illnesses, believe that God will perform miraculous healing, and attend faith-healing services[164,172,173]. Understanding that some AAs believe in divine intervention may help HCPs give better support to AAs with serious illness and their family members during EOL decision-making[174].

Death as a transition. Tenets of many religions view illness as a form of suffering[160] and death as transition into an afterlife[175,176]. Some AA Christians view suffering as a privilege because by suffering they become more like Christ, who also suffered[160]. For these AAs, suffering may be viewed as a positive transformative process that helps them become closer to God during the dying process. Additionally, some AAs believe that death exemplifies a transition into eternal peace and rest. In this context, AAs do not fear death; it is embraced[174]. To illustrate AAs' belief that death is a transitory state, one AA study participant commented, "I'm one of those people who don't believe that dying is it…when I'm absent from this body, I'll be present with the Lord. That gives me comfort[177]."

Although American society has changed drastically over the past 150 years, the AA community continues to face disproportionate struggles in many aspects of life[122]. The discussion of AA cultural values will now transition to AAs' tradition of struggle for survival and mistrust of the healthcare system.

Tradition of struggle for survival.

Minority healthcare disparities and discrimination. Through a long history of slavery, followed by Reconstruction, Jim Crow Laws, and the Civil Rights Movement, AAs have struggled for survival and freedom against fierce inequality, segregation, oppression, disenfranchisement, and discrimination[121,122,139,142,178]. AAs continue to face discrimination by HCPs, health institutions, and the healthcare system, which reflects social inequalities in the larger American society[179,180]. Healthcare disparities among minorities, including AAs, have often been associated with socioeconomic status[181], education[181], geographic location[182], and genetic conditions[183]; however, evidence suggests that minority patients also experience healthcare disparities due, in part, to discrimination within the healthcare system[180,183-191].

Perceptions of discrimination contribute to healthcare decision-making.

AAs often perceive discrimination in healthcare settings[183] and feel that they receive different, sometimes lower quality, medical treatment[192]. In fact, AAs are more than 14 times more likely than White Americans to report that they have received lower quality care and twice as likely than White Americans to state that discrimination is a problem in healthcare[192]. These perceptions of discrimination are not groundless, because overwhelming evidence has shown that minorities, including AAs, actually do receive lower quality and less intensive hospital care[193,194], fewer medical interventions[184,186,189,190,195-198], and inadequate pain management[191,199-201].

Strong perceptions of discrimination within minority communities are likely the result of discrimination many individuals have experienced in the larger American society. Past negative experiences outside the healthcare system can influence patient and family member healthcare behaviors inside the healthcare system[183]. Given AAs' struggle to survive longstanding inequality in American society, some AAs may overtly resist CFC because they perceive they are being denied an equal opportunity to receive life-prolonging, disease-oriented treatment[16,202]. When viewed through the prism of "survival", death is not inevitable, but yet another struggle to overcome[24,81,85,87,133,139,203,204]. This survival tradition may be a contributing factor in AAs' strong preference for LPT at EOL[12-16,19].

Medical mistrust. Though the Tuskegee Syphilis Study is a well-known example of American medical discrimination, it is not the first. The AA community has held strong beliefs of mistrust and fear of the medical community dating back to the 18th century[92]. Prior to the American Civil War, slaves and freed AAs were often used as subjects for dissection and medical experiments by medical schools[92,205]. Though White American subjects were also used, AA subjects were used far more often because of their availability, lower social status, and legal powerlessness. Fear among AAs

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regarding medical schools and dissection proliferated in the AA community and

continued past the antebellum period[92,205].

AA beliefs that their lives are undervalued by White American society negatively

influence their relationships with the medical profession, and provoke anger, frustration,

and mistrust[92,141]. AA mistrust of the healthcare system is well documented[14,83,87,90-96],

remains a major influence on AA perceptions of healthcare and decision-making

[87,167,206,207], and serves as a barrier to optimal EOL care[85]. Recognizing mistrust and

facilitating respectful approaches to initiate EOL conversations could improve

communication and promote informed decision-making among AA patients and family

members at EOL[32].

Underrepresentation of minority healthcare providers in end-of-life care.

Due to past and present inequalities in healthcare, it is understandable that many

minority patients would attribute their mistrust to racism in the healthcare system[85]. In

fact, one study reported that fears of the healthcare system are exacerbated by the lack

of diversity in healthcare institutions[136] and the absence of AA staff working in local

healthcare institutions[136]. Ethnic minorities report less respect and poorer

communication in race-discordant patient-family member-provider relationships, and

better communication and health outcomes in race-concordant relationships[208,209]. An

increased number of ethnically diverse HCPs can contribute to a welcoming environment

where AA patients encounter "friendly faces" who share an understanding of cultural

differences and fears. This increase may be an effective strategy to improve care for

AAs[136,208].

Patients', family members', and healthcare providers' prejudice and bias.

Patient-family member-provider perceptions can promote positive communication[21] or

serve as a barrier to patient care[20,21,210-212], including care at EOL[93]. For instance,

provider bias against minorities promotes patients' mistrust of the healthcare system[93].

Evidence suggests that in addition to reticent communication, AAs also express less positive perceptions of physicians than White Americans[213]. Several factors contribute to ethnic individuals' poor perceptions of care, including reactions to past mistreatment by HCPs and perceptions of HCP racism and prejudice[214].

Crawley et al. (2008) suggest that some individuals delay or avoid health procedures because of past racial or ethnic-based experiences in the medical setting[215]. Furthermore, HCPs' recommendations may be influenced by their own prejudices and bias[216]. Some medical professionals hold the same stereotypical views of the larger community[217]. Some White American HCPs have described AA patients as being less intelligent, more apt to engage in high-risk activities, and less compliant than White American patients[79]. Although additional research is necessary to explain the impact of HCPs' bias and patients' mistrust, the literature provides sufficient evidence that patient-family member-provider interactions and behaviors have contributed to health disparities in EOL care among AAs.

Limited Knowledge of Disease, Treatment, and Outcomes

In addition to medical mistrust, the decision to continue LPT has been associated with patients' limited knowledge of treatment outcomes and poor recall of prognostic discussions[97,99-101]. Patients' EOL care decisions, which are often based on an overestimation of long-term survival, reflect their limited knowledge about the disease diagnosis as well as the risks and benefits of treatment options[97]. Poor patient-family member-provider communication is a plausible explanation as to why HCPs' expectations of care contrast those of patients and family members[100]. Improved patient-family member-provider discussions regarding prognosis could help patients make informed treatment decisions that are more consistent with their values[97]. Improved patient-provider discussions are essential for AA patients, because they, like

many other patients, often have limited knowledge about treatment options, along with poor patient-family member-provider communication and interactions[12,79,106].

Limited Knowledge of End-of-Life Care Options

Many Americans[218,219], including AAs[98,220-224], do not use CFC and advanced directives because they have limited knowledge of these services[16,103,221,223,224]. Limited knowledge of the availability of CFC services, enrollment criteria, and contact information[102] serves as a barrier for AAs to access EOL care[16]. However, it can be overcome with adequate patient-family member-provider communication. Indeed, one study found that with greater exposure to information about hospice, one type of CFC, AAs reported more favorable beliefs associated with hospice[225]. Another study showed that when AAs are given adequate information about the benefits of CFC, they will consider using these services[226].

AAs have been documented as having less knowledge about hospice than White Americans. One study found that AAs reported significantly less exposure to information about hospice than their White American counterparts. In fact, 19% of AAs in this study had not heard of hospice compared to only 4% of White Americans. Another study found that more than half of its AA sample (n=19) had not heard of hospice. Patients and family members require appropriate education and prognostic information to understand the course of illness and plan for the future[227,228]. After receiving information about hospice, AAs have reported the need for a family member to receive care from hospice instead of receiving care from family members. Because knowledge of a healthcare service is a necessity for using the service, increasing knowledge among AAs may increase their use of CFC.

Other Characteristics: Age, Gender, and Religious Affiliation

Unsurprisingly, increased age is associated with higher rates of EOL care planning[229] and CFC use[17]. In 2011, more than 83% of hospice patients were 65 years

and older, while 33% were 85 years and older[17]. The average American life expectancy is now 77.9 years [230] as opposed to 47.3 years in1900[231].

With the bulk of the baby boomer generation reaching retirement age in the next decade, the U.S. elderly population is projected to explode. It is expected that there will be more than 88.5 million individuals over age 65 by 2050, representing 20% of the overall American population. Because the incidence of serious illness increases as individuals age, the number of individuals with serious illnesses such as cancer is estimated to double over the next 30 years[232]. As with incidence of serious illnesses, mortality from serious illnesses increases as an individual ages, making the question of how patients decide to shift the focus of care to CFC all the more important[247,248].

Gender, income, and education also have been shown to be related to CFC use. Women will comprise 63% of individuals 85 years and older by 2050. Among elderly populations, women use healthcare, including CFC, more often than men[233]. In 2011, more than half of hospice patients were women, and made up more than two-thirds of nursing home hospice decedents[17]. In addition to gender, income level also affects who uses CFC. Evidence suggests that individuals who have a higher income are more likely to use an advance directive and CFC than those with a lower income[239,240]. Likewise, individuals with higher education are more likely to use advance directives than individuals with less education[228,241-244].

Religious affiliation has also been associated with EOL care; however, study findings are inconsistent. Religious affiliation has been associated with using advance directives[223,234-237,245,246] and desiring LPT[238]. Conversely, having no religious affiliation has also been associated with advance directive use[239]. Additionally, there appear to be trends in the types of family members who provide EOL care for terminal patients. AAs family member involvement in care is consistent with national demographic trends among caregivers, which suggest that in the general U.S. population, caregivers are

generally female, 46 years of age, married, and working[240-243]. Among AAs, family

members who care for or make decisions for AA patients with serious illness tend to be

female and the spouse or the child of the patient[244,245]. In one study, caregivers for AA

patients with serious illness were the child of the patient (36%), spouse of the patient

(31%), and female (92%)[244]. Another study found that among AA patients, a daughter

was most likely to be an alternative decision-maker at EOL[245]. These findings are

important because family members often make EOL care decisions for family

members[246].

<center>**Patient-Family Member-Provider Interaction**</center>

Patient-Family Member-Provider Relationship

  The most important and often daunting goals of interactions between the patient,

family, and provider are to establish a good interpersonal relationship, exchange

information, and facilitate patient and family member involvement in decision-making[247].

Establishing these relationships is a dynamic, ongoing task that is critical insure optimal

medical care[1,248-250]. A quality patient-family member-provider relationship is one that

develops over time and is based on trust, rapport, respect, and communication[250].

Equally important to the patient-family member-provider relationship are mutual

understanding of the roles and responsibilities of all parties involved in care and patient

and family member involvement in decision-making[24,105,107,247,249-251]. Another important

element of a quality relationship is the acknowledgement of racial, ethnic, language, and

educational differences between patients, family members, and HCPs. Last, to promote

a quality healthcare relationship, it is important that HCPs genuinely "get to know"

patients and family members, as well as provide them with emotional support[247,250].

  Evidence suggests that strong patient-family member-provider relationships have

been associated with positive patient-family member outcomes, including enhanced

patient satisfaction, emotional health, patient adherence, reduced morbidity and mortality

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rates, effective patient trust, and patient-family member-provider communication[213,217,25724,252-255]. Patients are more inclined to establish a relationship with an HCP when their needs and expectations are met; however, when problems arise in the relationship, the quality of patient-family member-provider communication is negatively affected[256].

Quality of Communication

Communication may be considered the primary medium of healthcare delivery[251,257] and is thus an integral component of quality healthcare, especially at EOL[1,2,20,21,258,259]. Effective communication among patients, family members, and HCPs is essential for adequate symptom management, emotional adjustment, death and dying conversations, and patient and family member satisfaction[21,268]. However, minority patients generally report more difficulties communicating with HCPs[20,211,259]. Poor communication with HCPs about treatment impedes quality care and compromises adherence, informed decision-making, relationship building, trust, patient satisfaction, and healthcare outcomes[8,9,17,2121,22,215-217].

AA patient and family member communication challenges with HCPs are due to several factors, including reticent communication behaviors between AAs and HCPs[32,79,208], language differences[20,211,227,260,261], lack of HCP-provided information[1,20,40], and HCP avoidance of communicating bad news[102,112,269,271-273]. AA characteristics and interaction challenges with HCPs are interrelated, and although no direct causality has been conclusively proven, evidence suggests a link between these factors[24,247]. To improve healthcare outcomes for AA patients and family members, it is essential to explore how specific elements of the medical relationship and communication are affected by patient and family member characteristics.

Reticent communication. AA patients and family members have been documented to have limited, reticent communication while interacting with HCPs, which

is a major detriment to effective patient-provider relationships[32,79,208,260]. Furthermore, some AA patients have been perceived to express less affective and instrumental verbal behavior, be less assertive, and be unreceptive to social talk[79]. Conversely, some White American patients have been perceived as more expressive, friendly, responsive, and engaged during physician visits[12,32]. Some AAs perceive disrespect, rudeness, and condescending discourse by HCPs[208,211]. Furthermore, patients have stated they are ignored, have limited opportunity to ask questions, and do not receive essential health information from HCPs[79,211]. Many patients believed their poor treatment was because of race and ethnicity differences[211]. This perception is supported by data that show some HCPs tend to treat minority patients, especially AAs, with more verbal dominance and are less patient-centered in their approach to AA patients than White American patients[210]. Indeed, HCPs exhibit less emotional behavior, friendliness, and concern when communicating with ethnic minorities[82,111,216].

Since communication is the primary means by which HCPs gather and give information, reticent communication impedes the vital exchange of information, such as diagnosis, prognosis, and treatment options, all of which are directly related to positive patient healthcare outcomes[212]. As a result, AAs tend to be less compliant, have impaired patient-family member-provider relationships, report less satisfaction with decision-making, and experience overall worse medical outcomes[21,82,217,270]. AAs desire straightforward prognostic information; therefore, to help AA patients prepare for death and make important treatment decisions, it is imperative that HCPs use sensitive, open, and honest communication[102103,171102,212,262,263].

Medical language versus common language. The reticent communication observed between AA patients, family members, and HCPs could be a consequence of language barriers, which AAs routinely experience[211]. AAs, like other patients, have limited knowledge about basic biology and medical jargon. Therefore, they may have

difficulty understanding information given during healthcare interactions[260]. AAs often do

not fully understand the critical components of their care, such as diagnosis, prognosis,

or treatment options because HCPs use medical jargon[216,270]. In addition, patients often

have a poor recall of medical information concerning diagnosis, prognosis, and

treatment[260]. Eliminating medical jargon from discussions and tailoring information to

patient and family member needs may be an effective communication approach that

would help family members retain information, increase understanding, and improve

decision-making[20,210,227].

Lack of information and communication avoidance. Patients, family

members, and HCPs are hesitant about engaging in EOL discussions and often avoid

them[102,273]. HCPs communicate euphemistically and are overly optimistic about

prognosis. Due to their own feelings of loss or failure, HCPs delay EOL discussions in

an attempt to protect patients from bad news[102,269,271-273]. Many HCPs also believe that

EOL discussions will result in emotional upheaval for patients and family members,

however studies show that such discussions do not result in depressive symptoms or

eliminate hope[9,21]. Because HCPs try to protect patients and family members, HCPs

often do not communicate a poor prognosis until very late in the disease trajectory, or

not at all[40].

Evidence suggests that physicians do not communicate with many patients and

family members about EOL preferences, including AAs[1,40]. AAs routinely experience

poor communication and less satisfaction with decision-making because of limited EOL

discussions[20]. By avoiding giving bad news, HCPs deny patients and family members

the opportunity to define goals, set expectations, and make informed decisions[9,89,108,227].

Likewise, avoiding discussions can lead to mistrust, misuse of LPT, more medical

problems, and long hospital stays[7]. Conversely, facilitating discussions results in better

patient and family member understanding of the illness and its incurable prognosis, an

increase in do-not-resuscitate orders, and CFC use[10,275202].

Decision Outcomes

In the following section, the investigator will discuss the Ottawa Decision Support

Framework (ODSF) decision outcomes of decision regret and decisional conflict.

Decision Regret

Decision-making concepts from the ODSF were used to inform this study.

According to the ODSF, a quality decision is one that is informed, congruent with patient

and family member values, actualized, and results in patient and family member

satisfaction with decision-making[56,57]. Patients and family members may experience

decision regret when equally valued options are available and it is necessary to reject

one of the options. Regret has been defined in various ways and has often been

conflated with disappointment, sadness, and guilt[264-266]. The theory posits that regret is

a cognitive emotion that is derived from the knowledge that another outcome would have

been better than the one chosen, or from feeling self-blame for making a poor

decision[276,279,280]. Early studies of regret were conducted in business, sales, and

marketing, but regret has only recently been studied in the context of healthcare[267-270].

Regret has been measured in several healthcare intervention studies among men with

metastatic prostate cancer and women with breast cancer, however no study was found

that measured regret at EOL[284,286271].

There are several reasons for examining decision regret among AAs at EOL.

Decision regret has been associated with poor patient-family member-provider

communication, physician-made decisions (rather than shared decisions), and patients

receiving inadequate information to make decisions[74,271]. Evidence suggests that to

minimize decision regret, patients need information on treatment options and realistic

expectations of treatment outcomes[272]. Given that AAs often experience poor

communication with HCPs, receive inadequate information, and have insufficient

knowledge about diagnosis, prognosis, treatment and EOL options, studying decision

regret in this population would give insight into unmet needs. Needs can be met by

highlighting the type of communication and information AAs need to make appropriate

decisions. Information regarding AA communication and information needs could inform

future decision-making interventions.

Decisional Conflict

The ODSF uses concepts from several theories, including Decision Conflict

Theory. Decision Conflict Theory attempts to explain the behaviors individuals display

as they cope with the stress of making difficult decisions. According to Janis and Mann,

decisional conflict is "the simultaneous opposing tendencies within the individual to

accept and reject a given course of action (p. 46) [273]," and is likely to occur whenever an

individual has to make an important decision[273]. The primary construct of decisional

conflict is verbalized uncertainty, but decisional conflict may also include expressing

concern of undesired outcomes, delaying decisions, questioning personal values, and

oscillating between decisions[55,58]. If HCPs can identify patients or family members who

exhibit decisional conflict behaviors, such as verbalizing uncertainty or delaying

decision-making, they may be able to intervene and give these patients and family

members decision support[55].

Decisional conflict has been studied in various healthcare populations including

patients with heart disease, prostate cancer, and colorectal cancer; however, only five

studies were found that focused on EOL care, and only one was conducted among

AAs[291-294274-276]. One of these five EOL studies examined the reliability and validity of the

decisional conflict scale in a sample of end-stage heart failure and renal disease

patients[277]. Song and Sereika (2005) measured decisional conflict as a part of decision-

making and as a decision outcome at EOL[277]. The study found the decisional conflict

scale to have acceptable reliability (α = 0.81) when used to evaluate EOL decision-making[277]. In addition to the findings of Song and Sereika (2005), other studies showed the decisional conflict scale to be reliable, able to differentiate between patients who make or delay decisions, sensitive to change, and able to differentiate between various decision support interventions[55,58,288]. In order for this ODSF tool to be refined, further research is needed in diverse populations. This study addresses this need.

Summary

Evidence suggests that the AA EOL decisions are affected by patient and family member characteristics, including cultural values, religious values, mistrust of the healthcare system, age, gender, income, education level, and religious affiliation. Patient and family member knowledge about disease diagnosis, treatment options, and EOL care options also play roles in the decisions AAs make at EOL. Other relevant factors are patient-family member-provider communication and relationships. The two latter factors are especially important, because limited knowledge exists pertaining to quality of communication and decision outcomes; and virtually no evidence exists about family members' relationships with HCPs. Increasing knowledge of how these factors work together in AA decision-making could help investigators develop interventions that could increase CFC use among AAs and improve quality of life for patients and family members during the EOL care process.

Chapter Three

Methods

This chapter contains a comprehensive discussion of the methods that were used to examine African American (AA) family members' perceptions of the factors that influenced end-of-life (EOL) decision-making for their family member with a serious illness. This discussion includes the study design, sample and setting, study procedures, measures, data analyses, and the findings from a pilot feasibility study.

Human Subjects

This study was reviewed and approved by the Indiana University Purdue University Indianapolis (IUPUI) Internal Review Board (IRB).

Design

This mixed methods study combined both quantitative and qualitative descriptive approaches to examine AA family members' perceptions of the factors that influenced EOL decision-making for their family member with a serious illness. The following aims were addressed using quantitative and qualitative data collected during a one-time telephone interview:

Aim 1. *Describe characteristics of African American decedents' and bereaved family members', as well as bereaved family members' perceptions of quality of communication, end-of-life treatment decision, and decision outcomes.*

Aim 2. *Examine relationships among decedents' characteristics, bereaved family members' characteristics, quality of communication, end-of-life treatment decision, and decision outcomes.*

Aim 3. *Describe African American bereaved family members' experiences of end-of-life decision-making, quality of communication, and quality of relationships with healthcare providers.*

Aim 4. *Describe African American bereaved family members' perceptions of the decision to continue or discontinue life-prolonging treatment at the end-of-life.*

Setting

Bereaved family members were recruited from two locations: Eskenazi Health's Palliative Care Program, where their deceased relative received care at EOL, or from Eastern Star Church. The Eskenazi Health Palliative Care Program is a specialty care service within Eskenazi Health, a 315-bed safety net county hospital, which serves poor and minority populations in Marion County, Indiana. The Eskenazi Palliative Program uses the full team model approach to serve patients and family members with an interdisciplinary team of physicians, nurses, social workers, a spiritual advisor, and community volunteers. This hospital-based Palliative Care Program is a consultative service that provides care to patients and family members on inpatient units, as well as outpatient settings. The Palliative Care Program also works with local hospice programs and nursing homes to ensure continuity of care as patients and family members transition between inpatient and outpatient settings[278]. Eastern Star Church is a large, predominately African American church, with 15,000 members in the Indianapolis metropolitan area.

Sample

The sample consisted of the bereaved family members of deceased AA patients. In order to be eligible for participation, family members met the following criteria: aged 21 years or older; self-described as AA; related to the decedent by blood, marriage, or other close affiliation; reported being somewhat or very involved in the decedent's care in the last month of life; and able to speak and read English. Eligible decedents were: aged 21 years or older; identified as AA in the medical chart; received either comfort-focused care (CFC) or life-prolonging treatment (LPT) at a healthcare institution; died due to complications of a serious illness; and died within the past two to six months.

Sample Size

Since research is limited in this area, there was no statistical basis to approximate the sample size needed. To address study aims, 49 bereaved family members were enrolled. A sample size of 49 allowed for good estimates of reliability on the Ottawa Decision Support (ODS), Religious Beliefs and Values, and Quality of Communication instruments[279]. For, a subsample of 15 qualitative interviews were analyzed to address Aims 3 and 4. In order to identify the subsample of qualitative interviews, the sample was divided into three groups based on tertiles of total decisional conflict scores (e.g., low, moderate, and high scores). Each tertile was comprised of five qualitative interviews representative of each level of total decisional conflict scores.

Overall Study Procedures

In this section, study procedures regarding recruitment, data collection, measures, data analysis, and protection of human subjects are discussed.

Recruitment

To recruit bereaved family members from Eskenazi Health Palliative Care Program, the investigator collaborated with the Palliative Care Program's patient database director to identify eligible decedents and decedents' bereaved family members (those listed as next of kin). The identified family member of each eligible decedent was mailed an introductory letter from the Eskenazi Health Palliative Care Program medical director (see Appendix A), an information sheet containing elements of informed consent (see Appendix B), and a brochure explaining the study (see Appendix C). The letter included a telephone number to call and leave a message if family members were not interested in being contacted about the study.

One week after mailing the study packet, the investigator called family members who had not opted out to describe the study, answer questions, and invite participation. If the identified family members stated that they had not received the study information

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packet, then study information was provided verbally. If the participants wished to participate in the study, then a packet was mailed to them and an interview was scheduled for a convenient time for the participant. The investigator called participants who did not have a current address in the Eskenazi Health Palliative Care Program's database and requested an address in order to mail the study packet. If the participant did not have a current phone number or address in the Palliative Care Program's database, the investigator used US Search, a secure internet search engine, to attempt to locate participants' contact information. At the time of the initial telephone call the investigator determined eligibility, obtained verbal consent, and then proceeded with data collection if the participant was available (see Appendix D). If not, the interview was scheduled for a more convenient time for the participant.

Recruitment procedures varied at Eastern Star based on the request of church leadership. To recruit Eastern Star Church members, the investigator made a recruitment announcement to church members during a Saturday Senior Saints meeting. The Senior Saints is comprised of a group of elderly church members, aged 65+, which meets the third Saturday of each month to discuss Bible lessons and community events that impact elderly individuals. The investigator briefly described the study, then passed out study information sheets and brochures (see Appendices A and C). The investigator also described the study's eligibility criteria, answered questions, and invited members to participate in the study. Then, the investigator passed around a blank sheet of paper for members to provide their names and phone numbers if they were interested in participating in the study. The investigator called members who provided contact information, obtained verbal consent, determined eligibility, and asked members to provide their mailing address in order to mail thank you letters. The investigator proceeded with data collection at a time that was convenient for the participant.

Data Collection

All data were collected by phone. Once the participant verbally consented, the investigator conducted and audio taped each interview to assess perceptions of the factors that influenced EOL decision-making for his or her family member. First, the investigator asked participants to turn off televisions and/or radios to ensure a quiet setting for the interview[280]. Participants were given the option of taking a break during the interview if needed [280], to refuse to answer any questions that made them feel uncomfortable, and to withdraw from the study at any time without consequence, as their participation was completely voluntary.

Participants were asked to respond to questions about their perceptions of the factors that influenced EOL decision-making for their deceased family member with a serious illness, which could be upsetting and result in psychological harm. The investigator used the following strategies to minimize the risk of psychological harm: 1) included sample study questions in the introductory letter; 2) thoroughly explained everything to each participant; and 3) emphasized the voluntary nature of participation. The investigator also: 4) conducted the interviews in a professional manner; 5) repeated information when necessary; 6) informed participants that they did not have to answer any questions that made them feel uncomfortable; and 7) monitored the participants closely for cues that the participant was distressed. In the event that a participant became emotionally distressed, the investigator offered to terminate the interview and provide him/her with mental health and bereavement support information.

Next, the investigator administered the demographic survey, decision regret, decisional conflict, beliefs and values, and quality of communication measures (described below). In order to protect participants against the risk of a loss of confidentiality, interview data and questionnaires were labeled with identification numbers, rather than participants' names. All physical data forms were kept in a locked

file cabinet, while all digital data were saved on Indiana University's Research File System, a secure server that is password protected.

The qualitative portion of the interview was conducted using a 12-item semi-structured interview guide (described below). Family members' responses to the semi-structured interview guide were transcribed verbatim by professional transcriptionists from Absolute Marketing and Research, a trusted affiliate of the Indiana University School of Nursing. Following transcription, the investigator proofed transcripts for accuracy, and removed all identifying information. Transcribed data were saved in electronic format and password-protected on Indiana University's Research File System, a secure server that is password protected. Transcribed data was accessible only to the investigators, her advisors, and her consultant (Dr. Barbara Habermann).

Quantitative Measures

Patient and family member characteristics. Patient and family member characteristics assessed included age, gender, income, education level, relationship to decedent, religious affiliation, and religious values.

Characteristics. Quantitative characteristics were assessed by participant self-report using an 11-item investigator-developed survey. The following questions were asked to obtain each participant's and decedent's age, gender, income, years of education, and religious affiliation. Religious values were assessed only for participants, not for decedents.

Age. Age was assessed using the open-ended questions: "How old are you?" and "How old was your family member when s/he passed away?"

Gender. Gender of family members was assessed using the investigator's intuition of the sound of family members' voices and names.

Income. Income was assessed using the survey question: "Please stop me when I come to your total combined yearly household income before taxes. Is it…?"

Categorical response options ranging from 'less than $15,000' to 'more than $100,000' were read to each participant. (See Appendix D for all income categorical response options).

Years of education. Years of education were assessed using the question: "Please stop me when I come to the highest grade or year of school you finished. Is it….?" Categorical response options ranging from 'no school or kindergarten' to 'completed graduate degree' were read to each participant. (See Appendix D for all education categorical response options).

Relationship to decedent. Family members' relationship to the decedent was assessed using the open-ended question: "Please stop me when I come to the phrase that best describes your relationship to the family member? Where you his or her...?" Sample categorical response options included, "Husband", "Wife", Daughter or Step-daughter", and "Son or Step-son."

Religious affiliation. Religious affiliation was assessed using the open-ended question: "What is your religious affiliation?"

Religious values. Religious values of bereaved AA family members of decedents were measured using the Beliefs and Values Scale[52]. The 20-item scale measured spiritual and religious beliefs using a 5-point Likert response option, where zero = strongly disagree and four = strongly agree. The score for each item in the scale was summed to compute a total score, with a possible range of zero to 80. Higher scores indicated stronger spiritual and religious beliefs[52]. Sample Beliefs and Values Scale items included "I am a spiritual person," "I believe I have a spirit or soul that can survive my death," and "I believe in a personal God."

Quality of communication. Quality of communication was measured using the Quality of Communication Scale. The overall Quality of Communication Scale is comprised of two subscales: the General Communication Subscale (items 1-6) and the

EOL Communication Subscale (items 7-13). It contains 13-items sample items including: "How good was the healthcare team at using words you understood?" and "How good was the healthcare team at talking about what dying might be like?" [68] Response options ranged from 0 = "Poor" to 10 = "Absolutely Perfect[68]." The middle of the scale with the value of 5 = "Very Good." Response options also included "The healthcare team didn't do this" or "I don't know." These response options were appropriate if the family member felt members of the healthcare team could not be rated because communicative tasks were not performed, or if the family member did not know the answer to the scale item.

End-of-life treatment decision. End-of-life treatment decision was measured using a single item: "In the last month of life, was the goal of your loved one's treatment focused on keeping him or her comfortable or more towards trying to cure to him or her of the illness? For example, did the decedent receive comfort-focused care, such as hospice, or did they continue treatments to cure the illness?" Two categorical response options were 'comfort-focused care' or 'life-prolonging treatment'.

Decision outcomes.

Decision regret. Decision outcomes were measured using the Ottawa Decision Support (ODS) Decision Regret and Decisional Conflict Scales[48,50]. Decision regret was measured using the Decision Regret Scale[48]. The 5-item scale measured decision regret using a 5-point Likert response option, where one = "strongly agree" and five = "strongly disagree". Items two and four of the Decision Regret Scale were reverse coded so that, for each item, a higher number indicated more regret. To compute the total decision regret score for each family member, one was subtracted from each item total and multiplied by 25. Possible decision regret scores ranged from zero (no regret) to 100 (high regret). Sample scale items included "The decision to stop (or continue)

treatment was the right decision" and "I regret the choice about treatment that was made

for my loved one's end-of-life care[74]."

Decisional conflict. Decisional conflict was measured by the ODS Decisional

Conflict Scale[50]. The Decisional Conflict Scale measures personal perceptions of: a)

uncertainty in choosing options; b) amendable factors influencing uncertainty such as

feeling uninformed, unclear about personal values, and unsupported in decision-making;

and c) effective decision-making such as feeling the choice is informed, values-based,

and likely to be implemented, as well as expressing satisfaction with the choice[50].

This study used the 10-item low literacy Decisional Conflict Scale, which is most

useful for people with limited reading skills[50]. The 10-item scale measured decisional

conflict using questions with 3 response options, 'yes' = 0, 'no' = 4, and 'unsure' = 2[50].

To compute the total decisional conflict score, the scale's 10 items were summed,

divided by 10, and multiplied by 25. Possible decisional conflict scores ranged from zero

(no decisional conflict) to 100 (extremely high decisional conflict).

Table 2. Constructs, Instruments, and Number of Items

Construct	Measure (Author)	# of Items	Reliability from Published Literature
Demographics	Age, gender, income, education, religious affiliation (investigator-developed), etc.	11	N/A
Religious Values	Beliefs and Values Scale[52] (King)	20	0.94
Quality of Communication	Quality of Communication[68] (Engelberg) General Communication End-of-life Communication	6 7	0.91 0.79
End-of-life Treatment Decision	Investigator-developed question	1	N/A
Decision Regret	Decision Regret Scale[74] (ODSF)	5	0.81 to 0.92

Decisional Conflict	Decisional Conflict Scale[25] (ODSF)	10	0.86

Qualitative Measures

      The in-depth semi-structured interview consisted of open-ended questions derived from several domains that have been identified in the literature, including patient and family member knowledge of disease diagnosis, treatment options, treatment outcomes, and EOL options. Other important domains included the influences of religious values, cultural values, and medical mistrust. The patient-family member member-provider interaction variables of communication and relationships also informed interview questions. (See Appendix D for the complete interview guide).

<p align="center">**Data Analysis**</p>

Preparing the Quantitative Data for Analysis

      Quantitative data collected during the telephone interview were entered and stored in a REDCap database (Research Electronic Data Capture), a secure Web application for building and managing online surveys. Data were exported for analysis into the most current version of SPSS. Prior to data analyses to address the specific aims, univariate descriptive statistics were examined to check for accurate coding, missing data, out-of-range data, plausible means and standard deviations, and univariate outliers. The method for handling the missing data for any particular analysis depended upon the number of complete cases, number of variables with missing data, and the pattern of the missing data. If missing data for a particular variable or set of variables were few and missing completely at random, cases with missing data were deleted. If missing values were concentrated in a few variables, which were not critical to analysis, these variables were dropped. If data were missing at random, then standard methods can be applied as long as one controls for the variables related to the missingness. For example, if missingness of an outcome were related to age, we

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controlled for age in analyses. If missing data had a nonrandom pattern, then statistical modeling of the missing data beyond the scope of this study would be needed. Instead, it was treated as missing at random and acknowledged as a limitation in the discussion.

To detect outliers, histograms, box plots, and Q-Q plots were examined. In addition to outliers, variables were examined for normality, linearity, and homoscedasticity. Significance tests and normal probability plots for skewness and kurtosis were performed to determine distribution normality. Since the Shapiro-Wilk test is considered to be the most powerful normality test for all types of distributions and sample sizes[281-284], it was used to determine normality. Linearity was assessed by examining bivariate scatterplots. If variables failed tests of normality, linearity, and/or homoscedasticity, then data transformations were performed based on distribution deviation. Transformations included square root, logarithm, and inverse transformations. Variables with negative skewness were reflected, transformed, and then re-reflected. After transformations were performed, variables were examined for a normal or near-normal distribution. If variables were not normal after transformation, transformed variables were discarded and non-parametric methods were used with original variables.

Since statistical inference weakens as variables' distributions depart from normality, it is necessary to transform variables to improve normality. Screening continuous variables in multivariable analysis is important when inference is the goal. Normality of variables is assessed by statistical and/or graphical methods. Shapiro-Wilk tests ($p < .05$) and visual inspections of histograms, normal Q-Q plots, and box plots of all measures showed that none of the measures were normally distributed with the exception of Quality of EOL Communication. To normalize distributions, logarithmic, square root, and inverse transformations were applied to the following measures: Religious Beliefs and Values Scale, Quality of General Communication Scale, Decision Regret Scale, and Decisional Conflict Scale (see Appendix M). After applying

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logarithmic, square root, and inverse transformations to all non-normal measures, Shapiro-Wilk tests ($p < .05$) and visual inspections of histograms, normal Q-Q plots, and box plots showed that only the square root-transformations of the Religious Beliefs and Values Scale and Decision Regret Scale were normally distributed. Logarithmic, square root, and inverse transformations did not improve distributions of the Quality of General Communication Scale and Decisional Conflict Scale. Therefore, parametric methods (t-tests and Pearson correlation) were used in analyses that included the Quality of EOL Communication Scale, square root-transformed Religious Beliefs and Values Scale, and square root-transformed Decision Regret Scale, because these measures were normally distributed, and met all other parametric assumptions. Non-parametric methods (Mann-Whitney U tests and Spearman correlation) were used in analyses that included the Quality of General Communication Scale and Decisional Conflict Scale, because these measures were not normally distributed, even after transformations were applied (see Appendix M).

To conduct logistic regression analyses, quality of general communication and decisional conflict were dichotomized using a median split. Dichotomization is recommended when transformations do not render normal distributions[281-284]. Additionally, the Quality of General Communication Scale was dichotomized because the authors of this scale have experienced issues with the scale in the past. Specifically, participants have tended to rate items as either high (score of 10) or low (score of 0), with no intermediate ratings. The authors of the scale overcame this issue by dichotomizing the scale. It is important to note that such compression of Quality of EOL Communication Scale scores was not a problem in this study since participants rated items along the entire range of scores (0 to 10), including intermediate values. The Quality of EOL Communication Scale, square root-transformed Religious Beliefs and Values Scale, and square root-transformed Decision Regret Scale were not

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dichotomized because their linear residual plots were normally distributed in all linear models.

Cronbach alphas were calculated for both ODS scales, Religious Beliefs and Values Scale, and Quality of Communication Scales (general and EOL) (See Table 4 in Chapter 4). All item-to-total correlations were larger than 0.30 (data not shown). Descriptive statistics were run on all variables in order to characterize the sample with regard to demographics of the bereaved family member and decedent, religious values, quality of communication (general and EOL), decision regret, and decisional conflict.

Quantitative Data Analysis. Due to the exploratory nature of these analyses, no adjustments were made for multiple comparisons. All statistical tests were considered significant at a priori alpha level α = .05. The analyses for each aim and research question are presented below.

Aim 1. Describe characteristics of African American decedents' and bereaved family members', as well as bereaved family members' perceptions of quality of communication, end-of-life treatment decision, and decision outcomes.

To address Aim 1, descriptive statistics (mean and SD) and frequencies were performed on decedents' and bereaved family members' characteristics, and bereaved family members' quality of communication, EOL treatment decision, and decision outcomes. Decedents' and family members' income and education were collapsed into two categories for each variable. Decedents' income was collapsed into "$15,000 or less" and "More than $15,000". Family members' income was collapsed into "$30,000 or less" and "More than $30,000. Similarly, decedents' and family members' education were collapsed into two categories, "High School or Less" and "Post-secondary School". Decedents' and family members' income and education were collapsed into two categories because conducting analyses with the original variables would have violated

statistical assumptions, due to the study's small sample size. Specifically, assumptions

for chi-square tests for contingency tables would have been violated if expected cell

counts were less than one or when more than 20% of the contingency table cells had

expected cell counts less than five[285]. The collapsed income and education variables

were used in all statistical analyses.

Aim 2. Examine relationships among decedents' characteristics, bereaved
family members' characteristics, quality of communication, end-of-life
treatment decision, and decision outcomes.

To address Aim 2, Mann-Whitney U tests, t-tests, Spearman correlation tests,

Pearson correlation tests, Chi-Square tests, logistic regressions, and linear regressions

were performed to examine relationships among decedents' and family members'

characteristics, quality of communication with healthcare providers (HCP), EOL

treatment decision, and decision outcomes.

Research question 2a. *What are the relationships between decedents'*
characteristics and: 1) quality of communication; 2) end-of-life treatment decision;
and 3) decision outcomes?

Quality of general communication. Independent-sample Mann- Whitney U tests

were used to examine the relationships between decedents' gender (independent

variable [IV]), income (IV), education (IV), religious affiliation (IV), and quality of general

communication (dependent variables [DV]). Spearman correlations were used to

examine the associations between decedents' ages (IV), square root-transformed

religious values (IV), and quality of general communication (DV).

Quality of end-of-life communication. Independent-sample t-tests were used to

examine the relationships between decedents' gender (IV), religious affiliation (IV),

income (IV), education levels (IV), and quality of EOL communication (DV). Pearson

correlations were used to explore the associations between decedents' ages (IV), square root-transformed religious values (IV), and quality of EOL communication (DV).

End-of-life treatment decision. Independent-sample t-tests were used to examine relationships between decedents' ages (IV), square root-transformed religious values (IV), and EOL treatment decision (DV). Chi-square tests were performed to examine the relationships between decedents' gender (IV), incomes (IV), education levels (IV), and religious affiliation (IV) and EOL treatment decision (DV).

Decision regret. Independent-sample t-tests were used to examine the relationships between decedents' gender (IV), income (IV), education (IV), religious affiliation (IV) and square root-transformed decision regret (DV). Pearson correlations were used to explore the associations between decedents' ages (IV), square root-transformed religious values (IV), and square root-transformed decision regret (DV).

Decisional conflict. Independent-sample Mann- Whitney U tests were used to examine the relationships between decedents' gender (IV), income (IV), education (IV), religious affiliation (IV), and decisional conflict (DV). Spearman correlations were used to examine the associations between decedents' ages (IV), square root-transformed religious values (IV), and decisional conflict (DV).

Research Question 2b. *What are the relationships between bereaved family members' characteristics and: 1) quality of communication; 2) end-of-life treatment decision; and 3) decision outcomes?*

Quality of general communication. Independent-sample Mann- Whitney U tests were used to examine the relationships between family members' gender (IV), income (IV), education (IV), religious affiliation (IV), and quality of general communication (DV). Spearman correlations were used to examine the associations between family members' ages (IV), religious values (IV), and quality of general communication (DV).

Quality of end-of-life communication. Independent-sample t-tests were used to examine the relationships between family members' gender (IV), income (IV), education (IV), religious affiliation (IV), and quality of EOL communication (DV). Pearson correlations were used to explore the associations between family members' ages (IV), square root-transformed religious values (IV), and quality of EOL communication (DV).

End-of-life treatment decision. Independent-sample t-tests were used to examine relationships between family members' ages (IV), square root-transformed religious values (IV), and EOL treatment decision (DV). Chi-square tests were performed to examine the relationships between family members' genders (IV), incomes (IV), education levels (IV), and religious affiliation (IV) and EOL treatment decision (DV).

Decision regret. Independent-sample t-tests were used to examine the relationships between family members' gender (IV), income (IV), education (IV), religious affiliation (IV), and square root-transformed decision regret (DV). Pearson correlations were used to explore the associations between family members' ages (IV), square root-transformed religious values (IV), and square root-transformed decision regret (DV).

Decisional conflict. Independent-sample Mann-Whitney U tests were used to examine relationships between family members' gender (IV), income (IV), education (IV), religious affiliation (IV), and decisional conflict (DV). Spearman correlations were used to examine associations between family members' ages (IV), religious values (IV), and decisional conflict (DV).

Research question 2c. *What are the relationships among family members' quality of communication and decision outcomes?*

Spearman correlations were used to examine relationships between family members' quality of communication (IV), decision regret (DV), and decisional conflict (DV). Pearson correlations were used to examine associations between quality of EOL

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communication (IV) and square root-transformed decision regret (DV) because they were normally distributed.

Research question 2d. *Are there differences in decision outcomes by end-of-life treatment decision?*

An independent-sample t-test was used to examine differences in square root-transformed decision regret (DV) by EOL treatment decision (IV). Since decisional conflict was not normally distributed, an independent-sample Mann-Whitney U test was used to examine differences in decisional conflict (DV) by EOL treatment decision (IV).

Research question 2e. *Are there differences in quality of communication by end-of-life treatment decision?*

Independent-sample Mann-Whitney U test was used to test differences in EOL treatment decision (DV) by quality of general communication (IV). Since quality of EOL communication was normally distributed, an independent t-test was used to test differences in EOL treatment decision (DV) by quality of EOL communication (IV).

Research question 2f. *What antecedent and mediator variables in the conceptual model predict end-of-life treatment decision?*

Dichotomized variables were used to complete these analyses. Logistic regression was used to examine whether decedents' and family members' characteristics (IV), square root-transformed religious values scores (IV), dichotomized quality of general communication scores (IV), and quality of EOL communication scores (IV) predicted EOL treatment decision (DV). In multiple regression models, we controlled for any covariates that were potentially associated with the outcome (i.e. associated with the outcome with $p \leq .250$).

Research question 2g. *What antecedent and mediator variables in the conceptual model predict decision outcomes?*

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Dichotomized variables were used to complete these analyses. Given the square root-transformed religious values scores, quality of EOL communication scores, and square root-transformed decision regret scores were normally distributed, linear regressions were used to examine whether decedents' and family members' characteristics (IV), square root-transformed religious values scores (IV), dichotomized quality of general communication scores (IV), and quality of EOL communication scores (IV) predicted square root-transformed decision regret scores (DV). Logistic regression was used to examine whether decedents' and family members' characteristics (IV), square root-transformed religious values scores (IV), and dichotomized quality of general communication scores (IV) predicted dichotomized decisional conflict scores (DV). In the multiple regression models, we controlled for any covariates that were potentially associated with the outcome (i.e. associated with the outcome with $p \leq .250$).

Qualitative Data Analysis and Interpretation

Overview. Data were analyzed using qualitative descriptive methods and content analysis[286]. Using narrative methods emphasizes analysis within individual accounts and across-case coding. This allowed the investigator to understand bereaved family members, as well as develop a synthesis that captured variation across individuals[286]. Qualitative content analysis is analysis of verbal and visual data that is focused on summarizing the informational contents of the data[309,310]. Qualitative content analysis is considered the least interpretive of the qualitative analysis approaches because there is no obligation to re-present the data in terms other than in the participant's own words[287].

Sample size and sample selection for qualitative analyses. There is no universal rule for sample size in qualitative research. Sample size is largely a function of the purpose of the inquiry, the quality of the informants, and the type of sampling strategy used. Sample size should be determined based on informational needs, and

thus a guiding principle is data saturation, which is to sample until no new information is

obtained and redundancy is accomplished[288]. For the purposes of this study, a

subsample of 15 family members was selected in order to keep the scope of the project

feasible with the intent to conduct additional analyses on the remaining interviews at a

later date. Therefore, the analyses are preliminary. Saturation and redundancy was not

achieved.

Participants were selected based on their scores on the Decisional Conflict

Scale. Decisional conflict score was chosen as the criterion for sampling because

decisional conflict scores vary by individual[289], which could potentially give insight into

family members' perceptions of their loved ones' decisions to continue or discontinue

LPT at EOL. After a decisional conflict score was computed for each participant,

participants were divided into tertiles according to their decisional conflict summary

scores (see Table 3). The investigator randomly chose five participants from the lowest

tertile (reflecting low decisional conflict), five participants from the middle tertile

(reflecting moderate decisional conflict), and five participants from the highest tertile

(reflecting high decisional conflict).

Table 3. Frequencies of Decisional Conflict Tertiles

Total Sample (n = 49)		
Tertile	*n*	(%)
Low Decisional Conflict[a]	34	(69.4)
Moderate Decisional Conflict[b]	9	(18.4)
High Decisional Conflict[c]	6	(12.2)

[a]Decisional Conflict Score Range: 0-33.3
[b]Decisional Conflict Score Range: 33.4-66.6
[c]Decisional Conflict Score Range: 66.7-100

Analysis. De-identified, transcribed interviews were uploaded in to NVivo 10.0,

a qualitative software management system. This software helped the investigator to

organize and analyze the qualitative data that each participant provided. The

investigator created a case study for each interview to begin immersion into the data. After case studies were developed, the investigator read and re-read each transcript and gave labels to important ideas[290]. A preliminary code list was developed based off of this initial read and a data dictionary was created[291] (see Appendix K).

All interviews were read and coded by a primary (Esther Smith-Howell) and secondary (Susan Hickman) coder. The investigators read and labeled text data in the first five transcripts and then met together to compare labels and modify the data dictionary. The investigators read and labeled text data in five more transcripts, and then met together to refine the code set. The investigators continued this process for the final five transcripts. Differences in coding were discussed and resolved through consensus. The investigators met regularly to discuss coding interpretations and thematic analyses, and resolve discrepancies[291]. A methods expert, serving as a consultant, reviewed a subset of analyses for quality[292].

Once initial coding was complete, the primary coder reviewed all the qualitative data and identified the codes that were relevant to Aims 3 and 4. From these relevant codes, the primary investigator identified the codes that contained data from five or more participants. All participant quotes for each of these codes were reviewed and a memo for each code was developed that identified subthemes present in each code. Then subthemes across codes were synthesized to develop overarching themes related to Aims 3 and 4.

Summary

In this chapter, the investigator presented the methods used to conduct this study. The study design, sample and setting, study procedures, measures, and data analyses were presented. In this study, the investigator sought to improve end-of-life care among AAs with a serious illness and their family members by advancing our understanding of decision-making, patient- and family member-centered communication,

and patient and family member perceptions of the decision to continue or discontinue LPT at EOL. Because the investigator sought to capture decision-making from the perspective of the family member, the findings of this study generated valuable new knowledge that ultimately will lead to interventions to support different variations of decision-making and communication among AAs with a serious illness and their families.

Chapter Four

Results

This chapter presents the results of this study starting with a brief description of the sample and settings. The findings of the study will be discussed in two sections. First, discussion will address aims one and two, which were assessed using quantitative methods. The chapter concludes with a discussion of aims three and four, which were assessed qualitatively.

Sample and Settings

A convenience sample of 49 AA bereaved family members of AAs who died between 2 and 6 months ago were recruited to participate in this mixed methods study. As shown in Figure 3, 110 bereaved AA family members were identified as potentially eligible to participant in this study. Of the 110 family members, 74 were contacted and 36 were unable to be reached by phone. Three of the 74 individuals contacted were excluded due to ineligibility, resulting in a potential pool of 71 family members. Fifty family members enrolled in the study, 21 declined to participate. Forty-nine of the 50 family members' data were included in data analyses. One family member completed the qualitative portion of the interview, but was lost to follow-up to complete the quantitative portion. Therefore, data from this family member were excluded from all analyses. It is important to note that very few data were missing from analyses. Variables with missing data included decedents' and family members' income and education, and decedents' religious affiliation. Cases with missing data for these variables were deleted from analyses that involved these variables.

Figure 3. Recruitment Flow Diagram

Figure 3. Recruitment Flow Diagram
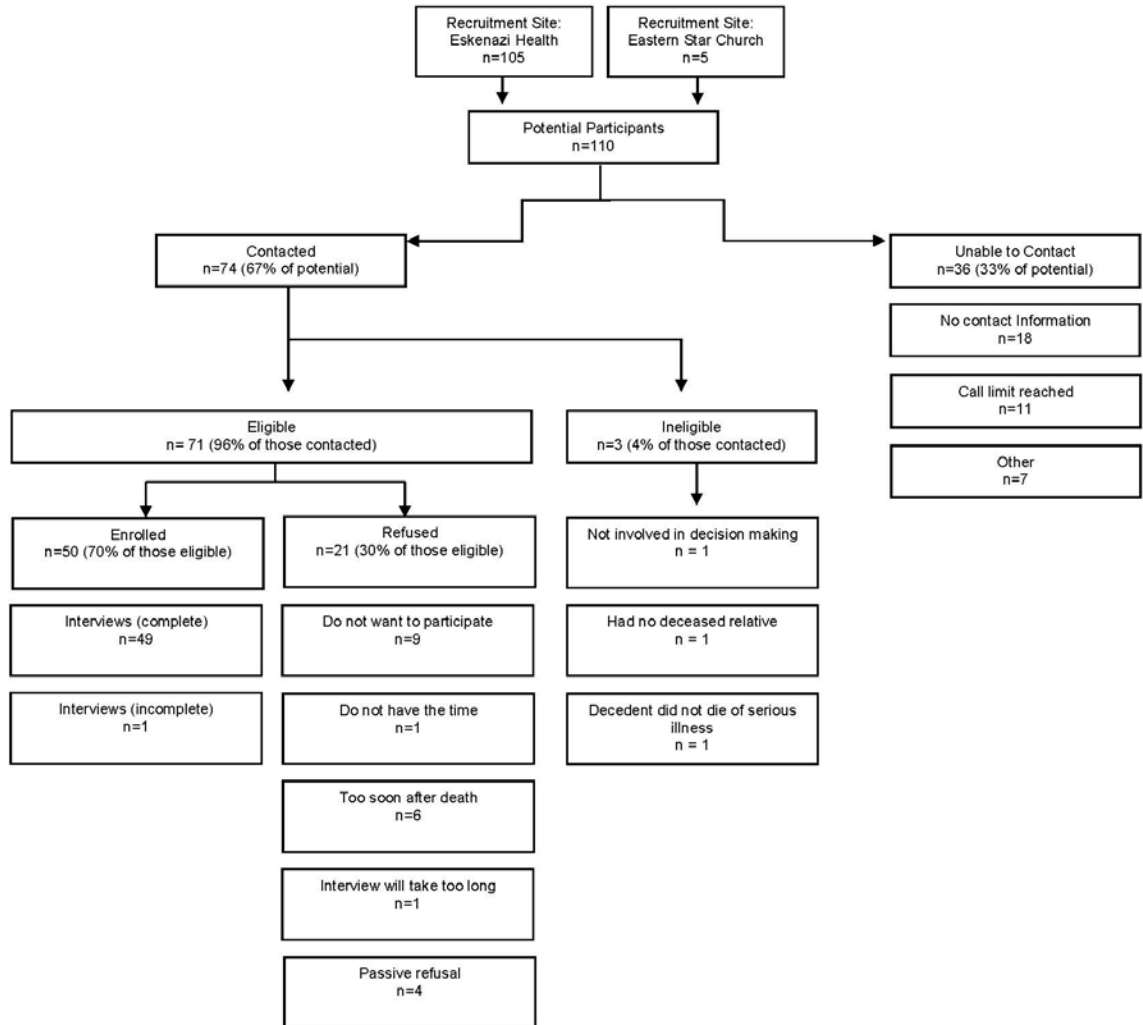
Aims and Research Questions

Aim 1. Describe characteristics of African American decedents' and bereaved family members', as well as bereaved family members' perceptions of quality of communication, end-of-life treatment decision, and decision outcomes.

Family members' characteristics. As shown in Table 4, family members ranged in age from 29 years to 81 years (M=52.3, SD=12.0). A majority of family members were female (67.3%) and the children of the decedents (55.1%). Most (73.5%) completed at least some college and had an annual income of $30,000 or less (48.9%). The sample's religious affiliation was almost completely Christian (95.9%). As shown in Table 5, family members had an average beliefs and values score of 64.6 (SD = 10.4).

Decedents' characteristics. As shown in Table 4, decedents' ages ranged from 38 years to 95 years (M=68.7, SD=12.1), with almost half (44.9%) being between 65-79 years old. The gender of decedents was almost evenly split; 25 were male and 24 were female. More than 70% of decedents had a high school education or less and 48.9% had an annual income of $15,000 or less. Nearly all decedents (97.9%) had a Christian religious affiliation.

Table 4. Family Members' and Decedents' Characteristics

Variable	Total Sample (n = 49) Family Members		Total Sample (n = 49) Decedents	
	n	(%)	n	(%)
<u>Age</u>				
0-34	2	(4.1)		-
35-49	19	(38.8)	4	(8.2)
50-64	19	(38.8)	14	(28.6)
65-79	8	(16.3)	22	(44.9)
80+	1	(2.0)	9	(18.4)
M (SD)	52.3	(12.0)	68.7	(12.1)
Range	29-81		38-95	
<u>Gender</u>				
Male	16	(32.7)	25	(51.0)
Female	33	(67.3)	24	(49.0)
<u>Annual Income</u>[a]				
$30k or Less ($15k or Less for decedents)	23	(48.9)	22	(48.9)
More than $30k (More than $15k for decedents)	24	(51.1)	23	(46.9)
<u>Education (grade)</u>[a]				
High School or Less	13	(26.5)	32	(71.1)
Post-secondary School	36	(73.5)	13	(28.9)
<u>Religious Affiliation</u>[a]				
Christian	47	(95.9)	46	(97.9)
None	2	(4.1)	1	(2.1)
<u>Relationship to Decedent</u>				
Husband	2	(4.1)		
Wife	5	(10.2)		
Daughter or Step-daughter	15	(30.6)		
Son or Step-son	12	(24.5)		
Daughter-in-law	4	(8.2)		
Sister	5	(10.2)		
Brother	2	(4.1)		
Niece	1	(2.0)		
Other Relative	1	(2.0)		
Friend	2	(4.1)		

[a]Missing values, were due to family members' refusals or lack of knowledge to answer.

Family members' perceptions of quality of communication, end-of-life treatment decision, and decision outcomes. As shown in Table 5, family members reported an average total quality of general communication score of 8.07 (SD = 2.13)

and an average total quality of end-of-life (EOL) communication score of 5.99 (SD =

2.78). Nearly two-thirds (63.3%) of decedents received CFC versus one-third (36.7%)

who received life-prolonging treatments (LPT) (Appendix H). The sample had an

average decision regret score of 22.2 (SD = 17.77) and an average decisional conflict

score of 25.4 (SD = 26.24). See Appendices E-J for tables of individual items of each

study measure.

Reliability of Study Measures

Participants completed the Religious Beliefs and Values Scale, Quality of

Communication Scale, Decision Regret Scale, and Decisional Conflict Scale.

Cronbach's alphas computed for each measure to assess internal consistency showed

each measure had a Cronbach's alpha of .70 or greater, which is an acceptable

reliability coefficient[34] (see Table 5).

Table 5. Reliability and Descriptive Statistics of Study Measures

Measure	*n*	*M*	SD	Range Potential	Range Actual	*α* (This Sample)
Religious Beliefs and Values	49	64.63	10.41	0-80	28-79	.905
Quality of Communication						
General	49	8.07	2.13	0-10	1.83-10	.938
End-of-life	49	5.99	2.78	0-10	0.14-10	.863
Decision Outcomes						
Decision Regret	49	22.24	17.77	0-100	0-80	.750
Decisional Conflict	49	25.41	26.24	0-100	0-90	.853

Note. Lower scores (0) indicate less strongly held beliefs, lower quality of
communication, less decision regret, and less decisional conflict.

**Aim 2. Examine relationships among decedents' characteristics, bereaved family
members' characteristics, quality of communication, end-of-life treatment
decision, and decision outcomes.**

**Research question 2a. What are the relationships between decedents'
characteristics and: 1) quality of communication; 2) end-of-life treatment
decision; and 3) decision outcomes?**

Since quality of general communication and decisional conflict were not normally
distributed, nonparametric methods (Mann-Whitney U tests and Spearman correlations)
were used to complete analyses for these two measures. Parametric methods
(independent sample t-tests and Pearson correlations) were used in analyses that
included quality of EOL communication and square root-transformed decision regret,
because both were normally distributed. Independent sample t-tests were used to
assess the differences in EOL treatment decision by decedents' age. Chi-square tests
were used to assess the differences in EOL treatment decisions by decedents' gender,
income, education, and religious affiliation.

Since quality of general communication and decisional conflict were non-normal
variables, Spearman correlations were necessary to assess the relationships between
decedents' age, quality of general communication, and decisional conflict. Since quality
of EOL communication, square root-transformed religious values, and square root-
transformed decision regret were normally distributed, Pearson correlations were
necessary to assess the relationships between decedents' age, quality of EOL
communication, and square root-transformed decision regret.

As shown in Table 6, family members of female decedents reported higher
quality of general communication scores than those of male decedents (Mean Rank =
30.12 vs. 20.08, p = .013). Decisional conflict scores approached significance for the
family members of male decedents versus the family members of female decedents
(Mean Rank = 28.80 vs. 21.04, p = .055). As shown in Table 6, there were no other
significant relationships between decedents' characteristics (income, education, and
religious affiliation) and family members' quality of general communication scores.

Likewise, there were no significant relationships between decedent's characteristics (gender, income, education, and religious affiliation) and family members' decisional conflict scores (Table 6).

As shown in Table 7a, family members of female decedents reported higher quality EOL communication scores than those of male decedents (M = 6.85 vs. 5.17, p = .033). Family members' decision regret scores were significantly higher for male decedents than female decedents (M= 4.97 vs. 3.34, p = .009). Differences in mean quality of EOL communication scores approached significance for family members of decedents who had Christian affiliation compared to family members of decedents who had no religious affiliation (M = 6.12 vs. 1.00, p = .069). It is important to note that 46 decedents had Christian affiliation compared to only one decedent who had no religious affiliation. Family members' decision regret scores approached significance for family members of decedents who had Christian affiliation compared to family members of decedents who had no religious affiliation (M = 4.22 vs. 0.00, p = .059). Again, it is important to note that 46 decedents had Christian affiliation compared to only one decedent who had no religious affiliation. As shown in Table 7a, there were no significant relationships between decedents' characteristics (income, education, and religious affiliation) and family members' quality of EOL communication scores and decision regret scores. There also was no significant relationship between decedents' age and EOL treatment decision (see Table 7b).

As shown in Table 8, the difference in proportions of respondents whose family member received LPT versus CFC by family members' education level approached significance (x^2 = 3.47, p = .062). Among family members with less education, a significantly larger proportion (85% versus 15%) of decedents received CFC versus LPT, compared to decedents of family members with higher education, whose proportions were nearly equal (56% versus 44%). There were no significant relationships between

decedents' characteristics (gender, income, education, and religious affiliation) and EOL

treatment decision. As shown in Table 10, family members' quality of EOL

communication scores were positively correlated with decedents' ages (r = .314, p =

.028). Specifically, family members' quality of EOL communication scores increased as

decedents' ages increased.

Table 6. Mann-Whitney U Tests of Differences in Family Members' Quality of General Communication and Decisional Conflict by Decedents' and Family Members' Gender, Income, Education, and Religious Affiliation

Outcome Variable	Characteristic	Mean Rank	n	U	Median	25th-75th Percentile	p
Quality of General Communication	**Decedent Gender**			**177.00**	**8.83**	**[7.00, 9.83]**	**.013**
	Male	**20.08**	**25**				
	Female	**30.12**	**24**				
	Decedent Income			223.00	8.83	[7.00, 9.83]	
	$15,000 or Less	24.36	22				.493
	More than $15,000	21.70	23				
	Decedent Education			171.00	8.83	[7.00, 9.83]	
	High School or Less	24.16	32				.352
	Post-Secondary School	20.15	13				
	Decedent Religious Affiliation			9.00	8.83	[7.00, 9.83]	.426
	Christian	24.30	46				
	None	10.00	1				
Decisional Conflict	Decedent Gender			205.00	20.00	[0.00, 40.00]	.055
	Male	28.80	25				
	Female	21.04	24				
	Income			225.50	20.00	[0.00, 40.00]	.527
	$15,000 or Less	21.75	22				
	More than $15,000	24.20	23				
	Education			204.50	20.00	[0.00, 40.00]	.929
	High School or Less	23.11	32				

Outcome Variable	Characteristic	Mean Rank	n	U	Median	25th-75th Percentile	p
	Post-Secondary School	22.73	13				
	Decedent Religious Affiliation			1.00	20.00	[0.00, 40.00]	.085
	Christian	23.52	46				
	None	46.00	1				
Quality of General Communication	Family Member Gender			227.00	8.83	[7.00, 9.83]	.428
	Male	22.69	16				
	Female	26.12	33				
	Family Member Income			253.50	8.83	[7.00, 9.83]	.631
	$30,000 or Less	23.02	23				
	More than $30,000	24.94	24				
	Family Member Education			190.00	8.83	[7.00, 9.83]	.317
	High School or Less	28.38	13				
	Post-Secondary School	23.78	36				
	Family Member Religious Affiliation			19.50	8.83	[7.00, 9.83]	.187
	Christian	25.59	47				
	None	11.25	2				
Decisional Conflict	Family Member Gender			214.50	20.00	[0.00, 40.00]	.286
	Male	28.09	16				
	Female	23.50	33				
	Family Member Income			239.00	20.00	[0.00, 40.00]	.425
	$30,000 or Less	25.61	23				

Outcome Variable	Characteristic	Mean Rank	n	U	Median	25th-75th Percentile	p
	More than $30,000	22.46	24				
	Family Member Education			183.00	20.00	[0.00, 40.00]	.243
	High School or Less	21.08	13				
	Post-Secondary School	26.42	36				
	Family Member Religious Affiliation			26.00	20.00	[0.00, 40.00]	.333
	Christian	25.45	47				
	None	14.50	2				

Table 7a. Independent Sample T-test of Differences in Family Members' Quality of End-of-life Communication Scores and Decision Regret Scores by Decedents' and Family Members' Gender, Income, Education, and Religious Affiliation

Outcome Variable	Characteristic	Mean	SD	*n*	*df*	*t*	*p*
Quality of End-of-life Communication	**Decedent Gender**						
	Male	**5.17**	**2.76**	**25**	**47**	**-2.19**	**.033**
	Female	**6.85**	**2.58**	**24**			
	Decedent Income						
	$15,000 or Less	6.06	2.83	22	43	0.28	.781
	More than $15,000	5.82	2.89	23			
	Decedent Education						
	High School or Less	6.08	2.82	32	43	1.01	.321
	Post-Secondary School	5.18	2.57	13			
	Decedent Religious Affiliation						
	Christian	6.12	2.71	46	45	1.87	.069
	None	1.00	-	1			
Decision Regret	**Decedent Gender**						
	Male	**4.97**	**1.95**	**25**	**47**	**2.75**	**.009**
	Female	**3.34**	**2.21**	**24**			
	Decedent Income						
	$15,000 or Less	4.32	2.24	22	43	.694	.491
	More than $15,000	3.84	2.34	23			
	Decedent Education						
	High School or Less	4.06	2.36	32	43	0.02	.982
	Post-Secondary School	4.04	2.10	13			
	Decedent Religious Affiliation						
	Christian	4.22	2.16	46	45	1.94	.059

Outcome Variable	Characteristic	Mean	SD	n	df	t	p
	None	0.00	-	1			
Quality of End-of-life Communication	Family member Gender						
	Male	5.30	2.80	16	47	-1.22	.230
	Female	6.33	2.75	33			
	Family Member Income						
	$15,000 or Less	5.98	2.91	23	45	0.10	.922
	More than $15,000	5.90	2.81	24			
	Family Member Education						
	High School or Less	7.10	2.41	13	47	1.71	.095
	Post-Secondary School	5.60	2.83	36			
	Family Member Religious Affiliation						
	Christian	6.10	2.79	47	47	1.34	.185
	None	3.43	0.61	2			
Decision Regret	Family Member Gender						
	Male	4.49	2.20	16	47	0.68	.498
	Female	4.02	2.24	33			
	Family Member Income						
	$15,000 or Less	4.46	2.05	23	45	1.08	.288
	More than $15,000	3.77	2.38	24			
	Family member Education						
	High School or Less	4.12	2.23	13	47	-0.11	.917
	Post-Secondary School	4.19	2.25	36			
	Family Member Religious Affiliation						
	Christian	4.20	2.26	47	47	0.42	.674
	None	3.52	0.50	2			

Table 7b. Independent Sample T-test of Differences in End-of-life Treatment Decision by Decedents' and Family Members' Age and Family Members' Religious Values

Outcome Variable	Characteristic	Mean	SD	*n*	*df*	*t*	*p*
	Decedent Age						
End-of-life Treatment Decision:	Comfort-focused Care	68.84	12.82	31	47	0.12	.902
	Life-prolonging Treatment	68.39	11.08	18			
	Family Member Age						
End-of-life Treatment Decision:	Comfort-focused Care	53.55	12.64	31	47	0.98	.331
	Life-prolonging Treatment	50.06	10.76	18			
	Family Member Religious Values						
	Comfort-focused Care	4.44	1.42	31	47	-0.61	.542
	Life-prolonging Treatment	4.69	1.31	18			

Table 8. Chi-Square Tests of Differences in End-of-life Treatment Decision by Decedents' and Family Members' Gender, Income, Education, and Religious Affiliation

Characteristic		Comfort-focused Care n (%)	Life-prolonging Treatment n (%)	Total n (%)	X^2	p
Decedent Gender	Male	16 (64.0)	9 (36.0)	25 (100)	0.01	.913
	Female	15 (62.5)	9 (37.5)	24 (100)		
	Total	31 (63.3)	18 (36.7)	49 (100)		
Decedent Income	$15,000 or Less	16 (72.7)	6 (27.3)	22 (100)	1.29	.256
	More Than $15,000	13 (56.5)	10 (43.5)	23 (100)		
	Total	29 (64.4)	16 (35.6)	45 (100)		
Decedent Education	High School/Diploma	21 (65.6)	11 (34.4)	32 (100)	0.55	.460
	Post-Secondary School	7 (53.8)	6 (46.2)	13 (100)		
	Total	28 (62.2)	17 (37.8)	45 (100)		
Decedent Religious Affiliation	Christian	28 (60.9)	18 (39.1)	46 (100)	0.63	.426
	None	1 (100.0)	-	1 (100)		
	Total	29 (61.7)	18 (38.3)	47 (100)		
Family Member Gender	Male	11 (68.8)	5 (31.5)	16 (100)	0.31	.579
	Female	20 (60.6)	13 (39.4)	33 (100)		
	Total	31 (63.3)	18 (36.7)	49 (100)		
Family Member Income	$30,000 or Less	16 (69.6)	7 (30.4)	23 (100)	0.64	.423

Characteristic		End-of-life Treatment Decision				
		Comfort-focused Care	Life-prolonging Treatment	Total		
		n (%)	n (%)	n (%)	X^2	*p*
	More Than $30,000	14 (58.3)	10 (41.7)	24 (100)		
	Total	30 (63.8)	17 (36.2)	47 (100)		
Family Member Education	High School/Diploma	11 (84.6)	2 (15.3)	13 (100)	3.47	.062
	Post-Secondary School	20 (55.6)	16 (44.4)	36 (100)		
	Total					
Family member Religious Affiliation	Christian	29 (61.7)	18 (38.3)	47 (100)	1.21	.271
	None	2 (100.0)	-	2 (100)		
	Total	31 (63.3)	18 (36.7)	49 (100)		

Research question 2b. What are the relationships between bereaved family members' characteristics and: 1) quality of communication; 2) end-of-life treatment decision; and 3) decision outcomes?

Since quality of general communication and decisional conflict were not normally distributed, nonparametric methods (Mann-Whitney U tests and Spearman correlations) were used to complete analyses for these two measures. Parametric methods (independent sample t-tests and Pearson correlations) were used in analyses that included quality of EOL communication, square root-transformed religious values, and square root-transformed decision regret, because all were normally distributed. Independent sample t-tests were used to assess the differences in EOL treatment decision by family members' age and religious values. Chi-square tests were used to assess the differences in EOL treatment decisions by family members' gender, income, education, and religious affiliation.

Since quality of general communication and decisional conflict were non-normal variables, Spearman correlations were necessary to assess the relationships between family members' age, quality of general communication, and decisional conflict. Since quality of EOL communication, square root-transformed religious values, and square root-transformed decision regret were normally distributed, Pearson correlations were necessary to assess the relationships between family members' age, square root-transformed religious values, quality of EOL communication, and square root-transformed decision regret.

As shown in Table 9, family members' quality of general communication scores were positively correlated with family members' ages (r_s = .290, p = .043). Specifically, family members' quality of general communication scores increased as their ages increased. As shown in Table 9, family members' religious values scores were positively correlated with family members' quality of general communication scores (r_s = .318, p =

.026). Specifically, family members' religious values scores increased as their quality of general communication scores increased. As shown in Table 9, family members' religious values scores were negatively correlated with family members' decisional conflict scores (r_s = -.285, p = .047). Specifically, family members' religious values scores increased as their decisional conflict scores decreased.

Table 10 shows that family members' quality of EOL communication scores were positively correlated with family members' ages (r = .311, p = .030). This indicates that family members' quality of EOL communication scores increased as their ages increased. As shown in Tables 6, 7a, 7b, and 8 there were no other significant relationships between family members' characteristics (age, gender, income, religious affiliation, and religious values) and quality of communication scores, EOL treatment decision, and decision outcomes. As shown in Table 10, family members' religious value scores were not significantly correlated family members' quality of EOL communication scores or decision regret scores.

Research question 2c. What are the relationships among family members' quality of communication and decision outcomes?

Spearman correlations were used to assess the relationships between family members' quality of communication scores (general and EOL), decision regret scores, and decisional conflict scores, because quality of general communication scores and decisional regret scores were not normally distributed. Although quality of EOL communication scores and decision regret scores were normally distributed, quality of general communication scores and decisional conflict scores were not normally distributed, therefore, Spearman correlations were necessary to assess the relationships between the normal and non-normal variables (see Table 9). Pearson correlations were used to assess the relationship between quality of EOL communication scores and

square root-transformed decision regret scores, because both were normally distributed (see Table 10).

Quality of general communication and decision outcomes. As shown in Table 9, family members' quality of general communication scores were negatively correlated with decisional conflict scores (r_s = -.503, p = .000). Specifically, as family members' general communication scores increased, their decisional conflict scores decreased. As shown in Table 9, family members' quality general communication scores were not significantly correlated with family members' decision regret scores.

Quality of EOL communication and decision outcomes. As shown in Table 9, family members' quality of EOL communication scores were negatively correlated with family members' decisional conflict scores (r_s = -.414, p = .003). Specifically, as family members' quality of EOL communication scores increased, their decisional conflict scores decreased. As shown in Table 10, family members' quality of EOL communication scores were not significantly correlated with family members' decision regret scores. Given the decision regret and decisional conflict scales are Ottawa Decision Support measures, they are highly correlated with one another[74]. Therefore, significant correlations between decision regret and decisional conflict were not reported as significant findings in this study (see Table 9).

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Table 9. Spearman Correlation of Decedents' and Family Members' Ages and Family Members' Religious Values Scores, Quality of Communication Scores, and Decisional Conflict Scores

Variable	1	2	3	4	5	6	7
1. Decedents' Ages	-	.361*	.253	.179	.243	-.252	-.187
2. Family Members' Ages		-	.045	.290*	.300*	.078	-.191
3. Religious Values			-	.318*	.177	-.201	-.285*
4. Quality of General Communication				-	.811**	-.241	-.503**
5. Quality of EOL Communication					-	-.084	-.414**
6. Decision Regret						-	.542**
7. Decisional Conflict							-

*p<.05, **p<.01

Table 10. Pearson Correlation of Decedents' and Family Members' Ages, and Family Members' Religious Values Scores, Quality of End-of-life Communication Scores, and Decision Regret Scores

Variable	1	**2**	3	**4**	5
1. Decedents' Ages	-	**.355***	.259	**.314***	-.211
2. Family Members' Ages		-	.058	**.311***	.056
3. Religious Values			-	.218	-.211
4. Quality of EOL Communication				-	-.057
5. Decision Regret					-

*p<.05

Research question 2d. Are there differences in decision outcomes by end-of-life treatment decision?

Since square root-transformed decision regret scores were normally distributed, an independent-sample t-test was used in analysis that included this variable. Since decisional conflict scores were not normally distributed, an independent-sample Mann-Whitney U test was used in analysis including this variable. As shown in Table 11, there were significant differences in decision regret scores between family members of decedents who received CFC versus those who received LPT (M = 3.65 vs. 5.07, p = .030). This finding indicates that family members of decedents who received CFC had less decision regret than family members of decedents who received LPT. As shown in Table 12, the difference in family members' decisional conflict scores by EOL treatment decision was not significant.

Table 11. T-tests of Differences in Family Members' Decision Regret Scores and Family Members' Quality of End-of-Life Communication Scores by End-of-Life Treatment Decision

Outcome Variable	Treatment Decision	*Mean*	*SD*	*n*	*df*	*T*	*p*
Decision Regret	**Comfort-focused care**	**3.65**	**2.09**	**31**	**47**	**-2.24**	**.030**
	Life-prolonging treatment	**5.07**	**2.20**	**18**			
Quality of End-of-Life Communication	Comfort-focused care	6.55	2.81	31	47	1.88	.066
	Life-prolonging treatment	5.04	2.51	18			

Table 12. Mann-Whitney U Tests of Differences in Family Members' Decisional Conflict Scores and Family Members' Quality of General Communication Scores by End-of-Life Treatment Decision

Outcome Variable	Treatment Decision	*Mean Rank*	*U*	*Median*	*25th-75th Percentiles*	*p*
Decisional Conflict	Comfort-focused care	23.05	218.50	20.00	[0.00, 40.00]	.204
	Life-prolonging treatment	28.36				

Outcome Variable	Treatment Decision	*Mean Rank*	*U*	*Median*	*25th-75th Percentiles*	*p*
Quality of General Communication	Comfort-focused care	27.42	204.00	8.83	[7.00, 9.83]	.118
	Life-prolonging treatment	20.83				

Research question 2e. Are there differences in quality of communication by end-of-life treatment decision?

Since quality of general communication scores were not normally distributed, an independent-sample Mann-Whitney U test was used in this analysis. Since quality of EOL communication scores were normally distributed, an independent t-test was used in this analysis. As shown in Table 11, the difference in quality of EOL communication scores for family members of decedents who received CFC versus those who received LPT (M = 6.55 vs. 5.04, p = .066) approached significance. As shown in Table 12, the difference in family members' quality of general communication scores by treatment decision was not significant.

Research question 2f. What antecedent and mediator variables in the conceptual model predict end-of-life treatment decision?

The square root-transformed religious values scores were used to complete these analyses, because this variable was normally distributed. Since quality of general communication scores were not normally distributed, it was dichotomized using a median split. In the multiple regression models, we controlled for any covariates that were potentially associated with the outcome (i.e. associated with the outcome with p ≤ .250).

Univariate and multivariable logistic regression analyses were used to predict family members' EOL treatment decision, using decedents' and family members' characteristics and family members' quality of communication scores (general and EOL)

as predictors. Religious affiliation was not used in these analyses because its limited

variation in this sample did not allow for use in regression analyses without violating

statistical assumptions. In a small sample, normally distributed errors allow investigators

to make inference about regression parameters. When errors are not normally

distributed, inferences are not reliable. The fact that only one to two decedents and

family members had no religious affiliation, makes this variable skewed (not normal),

and regression analyses performed using it would not be reliable[293]. Hence religious

affiliation was not used in regression analyses. As shown in Table 13, tests of individual

models against a constant only model showed that decedents' characteristic (age,

gender, income, and education), family members' characteristics (age, gender, income,

education, and religious values), as well as family members' quality of communication

scores (general and EOL) were not significant predictors of EOL treatment decision.

Table 13. Univariate and Multivariable Logistic Regression Analyses: Decedents' and Family Members' Characteristics and Family Members' Quality of Communication Scores as Predictors of End-of-life Treatment Decision

Outcome	Covariate	Univariate						Multivariable					
		B	SE	Wald X^2	p	Exp (B)	95% CI	B	SE	Wald X^2	p	Exp (B)	95% CI
EOL Treatment Decision	Decedent Age	0.00	0.03	0.02	.899	1.00	[0.95, 1.04]						
	Decedent Gender	0.07	0.60	0.01	.913	1.07	[0.33, 3.41]						
	Decedent Income	0.72	0.64	1.27	.260	2.05	[0.59, 7.15]						
	Decedent Education	0.49	0.67	0.54	.462	1.64	[0.44, 6.08]						
	Family Member Age	-0.03	0.03	0.97	.325	0.98	[0.93, 1.03]						
	Family Member Gender	0.36	0.65	0.31	.580	1.43	[0.40, 5.08]						
	Family Member Income	0.49	0.61	0.64	.425	1.63	[0.49, 5.44]						
	Family Member Education	1.48	0.84	3.12	.077	4.40	[0.85, 22.77]						

Outcome	Covariate	Univariate						Multivariable					
		B	SE	Wald X^2	p	Exp (B)	95% CI	B	SE	Wald X^2	p	Exp (B)	95% CI
	Family Member Religious Values	0.14	0.22	0.39	.534	1.15	[0.75, 1.77]						
	Quality of General Communication	-0.78	0.61	1.65	.199	0.46	[0.14, 1.51]	-0.59	0.63	0.87	.352	0.56	[0.16, 1.91]
	Family Member Age	-0.03	0.03	0.97	.325	0.98	[0.93, 1.03]						
	Family Member Gender	0.36	0.65	0.31	.580	1.43	[0.40, 5.08]						
	Family Member Income	0.49	0.61	0.64	.425	1.63	[0.49, 5.44]						
	Family Member Education	1.48	0.84	3.12	.077	4.40	[0.85, 22.77]	1.36	0.85	2.54	.111	3.89	[0.73, 20.60]
	Family Member	0.14	0.22	0.39	.534	1.15	[0.75, 1.77]						

Outcome	Covariate	Univariate						Multivariable					
		B	SE	Wald X^2	p	Exp (B)	95% CI	B	SE	Wald X^2	p	Exp (B)	95% CI
	Religious Values												
	Quality of EOL Communication	-0.21	0.11	3.24	.072	0.81	[0.65, 1.02]	-0.17	0.12	2.09	.149	0.84	[0.67, 1.06]
	Family Member Age	-0.03	0.03	0.97	.325	0.98	[0.93, 1.03]						
	Family Member Gender	0.36	0.65	0.31	.580	1.43	[0.40, 5.08]						
	Family Member Income	0.49	0.61	0.64	.425	1.63	[0.49, 5.44]						
	Family Member Education	1.48	0.84	3.12	.077	4.40	[0.85, 22.77]	1.27	0.86	2.19	.139	3.56	[0.66, 19.13]
	Family Member Religious Values	0.14	0.22	0.39	.534	1.15	[0.75, 1.77]						

Note. The dependent variable in this analysis is EOL treatment decision coded so that 0 = CFC and 1 = LPT.

Research question 2g. What antecedent and mediator variables in the conceptual model predict decision outcomes?

The square root-transformed religious values scores and square root-transformed decision regret scores were used in these analyses, because they were normally distributed. Since quality of general communication scores were not normally distributed, it was dichotomized using a median split. Similarly, decisional conflict scores were dichotomized using a median split. These two dichotomized variables were used in these analyses. In the multiple regression models, we controlled for any covariates that were potentially associated with the outcome (i.e. associated with the outcome with $p \leq .250$).

Univariate and Multivariable linear regression analyses were used to predict family members' decision regret scores using decedents' and family members' characteristics and family members' quality of communication scores (general and EOL) as predictors. Univariate and multivariable logistic regression analyses were used to predict family members' decisional conflict scores using decedents' and family members' characteristics and family members' quality of communication scores (general and EOL) as predictors. Religious affiliation was not used in these analyses because its limited variation in this sample did not allow for use in regression analyses without violating statistical assumptions.

Decedents' characteristics as predictors of family members' decision regret scores. As shown in Table 14, univariate and multivariable linear regression analysis showed that decedents' gender (p=.009) was a significant predictor of family members' decision regret scores. This finding indicates family members of male decedents had higher regret scores than those of female decedents. When decedents' gender (p=.022) and decedents' ages (p = .457) were entered into the multivariable model, decedents' gender remained a significant predictor of family members' decision

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regret scores (see Table 14). The multivariable model shows that decedents' gender and ages explained 11.2% of the variance in family members' decision regret scores. Univariate analysis shows that decedents' gender, alone, explained 12.0% of the variance in family members' decision regret scores. This indicates that decedents' ages add little explanation to the multivariable model. No other decedents' characteristics (age, income, and education) were significant predictors of family members' decision regret scores (see Table 14).

Family members' characteristics and quality of communication (general and end-of-life) as predictors of decision regret. As shown in Table 14, family members' characteristics (age, gender, income, education, and religious values) and quality of communication scores (general and EOL) were not significant predictors of family members' decision regret scores.

Table 14. Linear Univariate and Multivariable Regression Analyses: Decedents' and Family Members' Characteristics and Family Members' Quality of Communication Scores (General and End-of-Life) as Predictors of Family Members' Decision Regret Scores

Outcome	Covariate	Univariate					Multivariable				
		B	*SE*	*Beta*	*p*	95% CI	*B*	*SE*	*Beta*	*p*	95% CI
Decision Regret	Decedent Age	-0.04	0.03	-.021	.145	[-0.09, 0.01]	-0.02	0.03	-0.11	.457	[-0.07, 0.03]
	Decedent Gender	**-1.63**	**0.60**	**-0.37**	**.009**	**[-0.28, -0.44]**	**-1.49**	**0.63**	**-0.34**	**.022**	**[-2.75, -0.23]**
	Decedent Income	-0.47	0.68	-0.11	.491	[-1.85, 0.90]					
	Decedent Education	-0.02	0.75	-0.00	.982	[-1.54, 1.50]					
							Adjusted R²	0.11			
							F	4.02			
	Family Member Age	0.01	0.03	0.06	.704	[-0.4, 0.07]					
	Family Member Gender	-0.46	0.68	-0.10	.498	[-1.83, 0.90]					
	Family Member Income	-0.70	0.65	-0.16	.288	[-2.00, 0.61]					
	Family Member Education	0.08	0.73	0.12	.917	[-1.38, 1.54]					

Outcome	Covariate	Univariate					Multivariable				
		B	SE	Beta	p	95% CI	B	SE	Beta	p	95% CI
	Religious Values	-0.34	0.23	-0.21	.147	[-0.80, 0.12]					
	Quality of General Communication	-1.06	0.62	-0.24	.094	[-2.32, 0.19]	5.68	1.08	-0.19	.203	[-2.18, 0.48]
	Family Member Age	0.01	0.03	0.06	.704	[-0.04, 0.07]					
	Family Member Gender	-0.46	0.68	-0.10	.498	[-1.82, 0.93]					
	Family Member Income	-0.70	0.65	-0.16	.288	[-2.00, 0.61]					
	Family Member Education	0.08	0.73	0.02	.917	[-1.38, 1.54]					
	Religious Values	-0.34	0.23	-0.21	.147	[-0.80, 0.12]	-0.24	0.24	-0.15	.335	[-0.72, 0.25]
	Quality of EOL Communication	-0.05	0.12	-0.06	.698	[-0.28, 0.19]					
	Family Member Age	0.01	0.03	0.06	.704	[-0.04, 0.07]					

Outcome	Covariate	Univariate					Multivariable				
		B	*SE*	*Beta*	*p*	95% CI	*B*	*SE*	*Beta*	*p*	95% CI
	Family Member Gender	-0.46	0.68	-0.10	.498	[-1.83, 0.90]					
	Family Member Income	-0.70	0.65	-0.16	.288	[-2.00, 0.61]					
	Family Member Education	0.08	0.73	0.02	.917	[-1.38, 1.54]					
	Family Member Religious Values	-0.34	0.23	-0.21	.147	[-0.80, 0.12]					

Decedents' characteristics as predictors of decisional conflict. As shown in Table 15, decedents' characteristics (age, gender, income, and education) were not significant predictors of family members' decisional conflict scores.

Family members' characteristics as predictors of decisional conflict. As shown in Table 15, a test of the individual model against a constant only model was significant for family members' ages ($X^2 = 3.84$, p = .050). This finding indicates that family members' ages were significant predictors of family members' decisional conflict scores. When family members' ages (p = .069) and family members' education (p = .271) were entered into the multivariable model, neither remained a significant predictor of family members' decisional conflict scores. As shown in Table 15, no other family member characteristics (gender, income, and religious values) were significant predictors of family members' decisional conflict scores (see Table 15).

Family members' quality of general communication as predictor of decisional conflict. As shown in Table 15, a test of the each individual model against a constant only model showed that family members' quality of general communication scores ($X^2 = 7.04$, p = .008) and family members' ages ($X^2 = 3.84$, p = .050) were significant predictors of family members' decisional conflict scores. When family members' quality of general communication scores ($X^2 = 4.69$, p = .030) and family members' ages ($X^2 = 1.37$, p = .242) were entered into the multivariable model, family members' quality of general communication scores remained a significant predictor of family members' decisional conflict scores (see Table 15).

Nagelkerke's R^2 indicated that the multivariable model explained 23.3% of the variance in family members' decisional conflict scores. The prediction success overall was 71.4% (76.7% for *little to no conflict* and 63.2% for *moderate to high conflict*). Specifically, 76.7% of the observed cases were correctly classified for the *little to no decisional conflict* group and 63.3% of the observed cases were correctly classified for

the *moderate to high decisional conflict* group. Overall 71.4% observed cases were correctly classified, which is an improvement on the 61.2% correct classification with the constant model.

The EXP(B), odds ratio, indicates that when family members' quality of general communication scores increase by one point, the odds of being in the *moderate to high decisional conflict* group decrease by 0.23. This indicates that when family members' quality of general communication scores are higher, family members are less likely to have moderate to high decisional conflict.

Quality of end-of-life communication as predictor of decisional conflict. As shown in Table 15, a test of each individual model against a constant only model showed that family members' quality of EOL communication scores ($X^2 = 8.23$, p = .004) and family members' ages ($X^2 = 3.84$, p = .050) were significant predictors of family members' decisional conflict scores. When family members' quality of EOL communication scores ($X^2 = 6.07$, p = .014) and family members' ages ($X^2 = .1.14$, p = .286) were entered into the multivariable model, only family members' quality of EOL communication scores remained a significant predictor of family members' decisional conflict scores.

Nagelkerke's R^2 indicates that the multivariable model explained 28.7% of the variance in family members' decisional conflict scores. The overall prediction success for family members' decisional conflict scores was 73.5% (86.7% for *little to no conflict* and 52.6% for *moderate to high conflict*). Specifically, 86.7% of the observed cases were correctly classified for the *little to no decisional conflict* group and 52.6% of the observed cases were correctly classified for the *moderate to high decisional conflict* group. Overall 73.5% were correctly classified, which is an improvement on the 61.2% correct classification with the constant model.

The EXP(B), odds ratio, indicates that when family members' quality of EOL communication scores increase by one point, the odds of being in the *moderate to high decisional conflict* group decrease by 0.71. This indicates that when family members' quality of EOL communication scores are higher, family members are less likely to have moderate to high decisional conflict.

Table 15. Univariate and Multivariable Logistic Regression Analyses: Decedents' and Family Members' Characteristics and Family Members' Quality of Communication Scores (General and End-of-Life) as Predictors of Family Members' Decisional Conflict Scores

Outcome	Covariate	Univariate						Multivariable					
		B	SE	Wald X^2	p	Exp (B)	95% CI	B	SE	Wald X^2	p	Exp (B)	95% CI
Decisional Conflict	Decedent Age	-0.01	0.03	0.26	.611	0.99	[0.94, 1.04]						
	Decedent Gender	-0.45	0.59	0.58	.445	0.64	[0.20, 2.03]						
	Decedent Income	0.30	0.61	0.24	.627	1.35	[0.41, 4.46]						
	Decedent Education	-0.30	0.70	0.18	.670	0.74	[0.19, 2.94]						
	Family Member Age	**-0.05**	**0.03**	**3.84**	**.050**	**0.95**	**[0.90, 1.00]**	-0.05	0.03	3.31	.069	0.95	[0.90, 1.00]
	Family Member Gender	-0.69	0.62	1.24	.265	0.50	[0.15, 1.69]						
	Family Member Income	0.29	0.60	0.24	.628	1.34	[0.41, 4.36]						
	Family Member Education	0.98	0.74	1.76	.184	2.67	[0.63, 11.35]	0.84	0.77	1.21	.271	2.32	[0.52, 10.41]
	Religious Values	-0.06	0.22	0.08	.775	0.94	[0.62, 1.44]						

Outcome	Covariate	Univariate						Multivariable					
		B	*SE*	*Wald X²*	*p*	*Exp (B)*	95% CI	*B*	*SE*	*Wald X²*	*p*	*Exp (B)*	95% CI
	Quality of General Communication	**-1.72**	**0.65**	**7.04**	**.008**	**0.18**	**[0.05, 0.64]**	**-1.47**	**0.68**	**4.69**	**.030**	**0.23**	**[0.06, 0.87]**
	Family Member Age	**-0.05**	**0.03**	**3.84**	**.050**	**0.95**	**[0.90, 1.00]**	-0.35	0.03	1.37	.242	0.97	[0.91, 1.02]
	Family Member Gender	-0.69	0.62	1.24	.265	0.50	[0.15, 1.69]						
	Family Member Income	0.29	0.60	0.24	.628	1.34	[0.41, 4.36]						
	Family Member Education	0.98	0.74	1.76	.184	2.67	[0.63, 11.35]						
	Religious Values	-0.06	0.22	0.08	.775	0.94	[0.62, 1.44]	R²	0.23				
								n	49				
	Quality of EOL Communication	**-0.39**	**0.13**	**8.23**	**.004**	**0.68**	**[0.52, 0.89]**	**-0.34**	**0.14**	**6.07**	**.014**	**0.71**	**[0.55, 0.93]**
	Family Member Age	**-0.05**	**0.03**	**3.84**	**.050**	**0.95**	**[0.90, 1.00]**	-0.03	0.03	1.14	.286	0.97	[0.91, 1.03]
	Family Member Gender	-0.69	0.62	1.24	.265	0.50	[0.15, 1.69]						

Outcome	Covariate	Univariate						Multivariable					
		B	*SE*	*Wald X²*	*p*	*Exp (B)*	95% CI	*B*	*SE*	*Wald X²*	*p*	*Exp (B)*	95% CI
	Family Member Income	0.29	0.60	0.24	.628	1.34	[0.41, 4.36]						
	Family Member Education	0.98	0.74	1.76	.184	2.67	[0.63, 11.35]						
	Religious Values	-0.06	0.22	0.08	.775	0.94	[0.62, 1.44]						
								R^2	0.29				
								n	49				

Note. The dependent variable in this analysis is decisional conflict coded so that 0 = "Little to No Conflict" and 1 = "Moderate to High Conflict.

Aim 3. Describe African American bereaved family members' experiences of end-of-life decision-making, quality of communication, and quality of relationships with healthcare providers.

Several codes emerged that related to each antecedent and mediator variable that was assessed qualitatively. However, for the purposes of this dissertation, an analytic decision was made by the research team to focus on codes with representation from at least one-third (five interviews) of the sample. A complete list of codes and the coding dictionary are available in Appendix K. The dominant themes relevant to aim 3 included, U*nderstanding*, *Relationship with the Healthcare Team*, and *Quality of Communication.*

Understanding.

The notion of understanding or a lack of understanding about diagnosis, treatment options, treatment outcomes, and end-of-life care options emerged as a central theme. Family members' comprehension of the severity of decedents' illnesses was important to decision-making, as well as their preparedness for decedents' deaths. Within this "parent" theme, seven subthemes emerged as important to Understanding in the context of family members' EOL decision-making. These subthemes included *Diagnosis, Treatment Options, Treatment Outcomes, Change in Condition, Prepared for Death, Unprepared for Death,* and *Lack of Understanding*.

Diagnosis. Communication emerged as a crucial aspect of family members' understanding of decedents' diagnoses. Indeed, when family members lacked understanding regarding diagnoses, poor family member-provider communication was often the origin of their deficient comprehension. Family Member 39, the spouse of a decedent, poignantly illustrated how poor communication contributed to her poor understanding by saying, "To tell you the truth the doctors wasn't telling us anything, so I'm not sure exactly what was his diagnosis." It was equally important that family

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members be involved in discussions pertaining to decedents' diagnosis and treatment options. Inclusion in these discussions served as catalysts to family members' understanding decedents' diagnoses, which in turn, helped them to comprehend the severity of decedents' illnesses.

Treatment Options. Similarly to providing information about diagnoses, the information that HCPs communicated to family members about treatment options helped to structure family members' understanding of decedents' illnesses. Specifically, the manner that HCPs conveyed information (i.e., optimistically) swayed how family members perceived and understood decedents' treatment options. Family Member 47, recalled HCPs' hopeful communication about her mother's illness stating, "They never ever said that they felt like my mother wasn't going to make it. They still were talking about positive things going forward." In addition to communicating optimistically, HCPs who told family members the treatments decedents would receive, rather than including family members in care discussions and decision-making also contributed to family members' comprehension (or lack of comprehension) of decedents' treatment options. Family Member 8 recalled his experience of this type of poor communication when he stated:

> "As far as I can remember, the only thing they mentioned the best thing for us to do is to do some chemo treatments, and see how that goes from there. What they didn't say, we could try this and this and here's another option or here's a different option. There wasn't nothing else given. It was just, you're going to go along with these type of chemo treatments and that's it."

The limited information he received regarding treatment options contributed to his misunderstanding of how sick the decedent actually had become. In fact, he was surprised when the decedent died.

Treatment Outcomes. The information that HCPs communicated regarding the possible outcomes of decedents' treatments influenced family members' expectations of

treatments, and also affected their decision-making. Furthermore, family members'

expectations of the efficacy of treatments played a crucial role in their acceptance of

treatment outcomes. To illustrate, Family Member 6 recalled how her conversations with

HCPs helped her to understanding the futile nature of LPT. She stated, "But as far as

the diagnosis it was too far gone. It would be a waste of time and money to even try to

treat it. Her body was too fragile to go through all of the treatment." In addition to the

information family members received from HCPs, sometimes family members' emotional

state affected their decision-making. Specifically, hope for a positive outcome blinded

some family members to the reality of decedents' actual treatment outcomes. These

family members were in denial and had difficulty accepting poor outcomes. Regarding

her mother's treatment, Family Member 35 stated:

> The first part of her diagnosis, I was still in denial. I thought, oh she's
> going to get better. Because she was going to complete the chemo and
> the radiation. So she was staying with the program for quite a while, for
> at least less 6 months. So I was saying, "oh she's going to come out of
> it." And all that, and of course she a big turnaround, because of course
> she was being treated. So, she was talking better, she was eating better;
> she was getting back to…but then, reality sunk in, probably at the later
> part of 2013 the early part of 2014.

This family member had to accept the painful reality that treatments would not save her

mother's life.

   Changes in Condition. Another important aspect of family members'

understanding was their ability to recognize and make sense of the changes in

decedents' conditions. Family members' cognizance of decedents' physical and

cognitive changes influenced the decisions they made on decedents' behalves. Some

family members were educated about the meaning of changes by HCPs, whereas others

intuitively recognized the meaning of changes. One family member (23) recalled how

she saw changes in the decedent's condition when she said:

> At first I thought he was doing fine, and then all at once he started getting
> weaker and sicker. He started losing his bowels. I thought he was doing

better, but he wasn't, and then all of the sudden he wasn't responding.
He was too weak. He had quit eating and anything, and he just had quit
responding at all, and then about a week he passed.

In some instances, family members fully comprehended that all medical options had

been exhausted and accepted that decedents' deaths were imminent. On the other

hand, other family members never understood that death was approaching until after

decedents had died.

Prepared for Death. Family members' preparedness for decedents' deaths was

affected by the information they received from HCPs, decedents' physical decline, and

decedents' attitudes towards death. Family members depended on HCPs to inform

them of what to expect as decedents actively died, particularly the physical changes that

decedents would experience. In addition to finding this information helpful to prepare for

death, family members appreciated this information because it helped them feel comfort

with and accept decedents' deaths. The daughter (Family Member 25) of a decedent

expressed her gratitude for the information HCPs provided to her regarding the physical

changes she could expect as her mother neared death. She stated:

I think with their knowledge of a person's passing, the doctor was right to
the point, even to the date, so that was really, really helpful for us, but like
I said, when she came in, they took really good documentation along with
the nurses and everything, but I felt like it was better for us to know up
front than to be surprised, even with the foot. She told us how it would
just literally die, and it did. She said you could look at it one hour, and the
next hour it could be worse, and it was, so I really appreciated that.

In addition to information from HCPs, decedents' attitudes about their own impending

deaths helped family members' preparedness. Specifically, when decedents were at

peace with their own deaths, family members were better able to accept the deaths.

Regarding her mother's death, Family Member 25 went on to say, "It was very painful.

It's very painful still, but the peace comes when you realize that she was at peace with

it."

Unprepared for Death. The information, or lack of information, that HCPs conveyed to family members regarding decedents' diagnoses and treatment options was integral to family members' comprehension of the severity of decedents' illnesses. When HCPs did not provide family members with sufficient information that alerted them that decedents would soon experience physical decline, family members sometimes chose treatments that did not match decedents' actual care needs.

Some family members were unprepared because they perceived decedents' deaths to have occurred extremely quickly, which left little time to obtain or process the information about decedents' deaths. Rapid deaths often occurred when decedents had late-stage diagnoses. Family members of decedents with late-stage diagnoses felt they had to "juggle" many issues simultaneously, such as handling logistical matters surrounding decedents' funerals, burials, and care plans. Handling several issues at once left family members limited time to absorb the reality of decedents' diagnoses and/or impending deaths.

Lack of Understanding. When HCPs gave family members inadequate information, family members often did not fully comprehend the severity of decedents' illnesses, what treatments were available, or the outcomes of treatments that decedents received. Family Member 26 regretted the limited information he and his father received regarding treatment outcomes. He stated:

> I think him not being able to walk really affected his, I don't know, happiness. It caused some other things, like lack of bowel functions. He couldn't take care of himself in that sense and I think it really messed with his self-esteem, his confidence and he went into depression. And I don't think that was clearly explained, that he may lose his ability to walk. That seemed pretty serious. It may have been mentioned once, but I think it could have been mentioned more.

This family member's description of his father's experiences alluded to the important role that information played in his understanding of treatment options.

Relationship with the Healthcare Team.

How family members' relationships with healthcare teams influenced their decision-making. Family members' relationships with healthcare teams emerged as a second major theme relevant to understanding AA family members' EOL decision-making experiences. Positive relationships were described as being based on clear, honest, trustworthy, and continuous communication that gave complete information. Family members' expectations of care included competent, prompt, and attentive care. Beyond these expectations, family members desired relationships that provided them with emotional stability. Specifically, they wanted comfortable relationships that quelled their fears and instilled trust in the care that HCPs delivered. The overarching theme "Relationship with Health Care Team" included six subthemes: *Being Shown Care*, Available and Attentive, *Distrusting, Trusting, HCP Had Expertise, and Perceived Substandard or Incompetent Care*.

Being shown care. Family members reported their relationships with healthcare teams were positive when family members perceived HCPs to show that they cared about decedents, as well as family members. Family members felt that they were being shown care when HCPs communicated with them and kept them abreast of decedents' conditions. Family members described HCPs' exhibitions of care in several ways, including through kind gestures such as providing family members with warm blankets or offering to warm decedents' food. In addition to kind gestures, family members felt that when HCPs showed them respect, empathy, and sympathy during interactions, they were shown care. To illustrate, Family Member 40 recalled feeling that HCPs cared when she stated:

> A couple of them even prayed with us. So when people are praying for you, you get the sentiment that they really care and I think that's the main thing, we got the sense that they really cared because of how they treated us, and they treated us with respect.

Available and attentive. Another salient subtheme that emerged was the notion that HCPs were available to speak with family members and attentive to decedents' needs. HCPs' availability and attentiveness, or the lack thereof, was especially pronounced when decedents were actively dying. During this time, family members desired to have HCPs available to answer questions, provide pertinent information, and attend to decedents' needs as death approached. Furthermore, when HCPs proactively called family members or promptly returned their phone calls, family members appreciated the deliberateness with which HCPs' showed care. Family member 4 recalled her positive experiences in her relationship with HCPs when she stated:

> If I needed anything I got it the same day. I felt very supported. I could call his nurse day or night, no matter what time of day. If he needed something or if I needed something they were very attentive to the needs. They were wonderful.

The statement above embodies the notion of HCPs' availability and attentiveness.

Distrusting. Family members developed distrust in HCPs when HCPs failed to inform them of potential risks and complications of the treatments decedents received. Additionally, when family members interacted with one HCP, rather than a team of HCPs, family member perceived communication with the healthcare team, as a whole, to be poor. This idea of poor communication is illustrated by Family member 39. She stated:

> I didn't trust the team at all. I mean the only person I valued was Dr. X. Now he's the only person that I can speak of, that when think of a team, I mean what team? I never really met the team.

When family members perceived decedents had received incompetent care (i.e., HCPs made medical errors), they distrusted and felt HCPs had not given their best effort to provide optimum care. This sentiment was aptly exemplified when Family Member 47 said, "I mean she had to be there, and I had to trust that they were doing their best, but in my heart and in my gut I didn't feel like they were."

Trusting. Just as incompetent and substandard care provoked family members to distrust HCPs, the opposite was true for family members' trust in HCPs. Indeed, family members trusted HCPs who exhibited medical competence, ensured decedents' physical need were met (i.e., sanitized rooms, bathed regularly), and kept family members informed regarding decedents' conditions. Also, HCPs who were not hurried in their interactions with family members and decedents garnered their trust. To add, family members who preferred that decedents receive LPT, felt they could trust HCPs whom they believed genuinely attempted to save decedents' lives.

Healthcare provider had expertise. In addition to trusting HCPs who gave competent care, family members respected HCPs whom they perceived to have medical expertise. HCPs exhibited expertise with accurate diagnoses, prognoses, and when they provided family members with instrumental support, such as teaching them how to care for decedents' physical needs (i.e., taught how to clean feeding tube). Family Member 48 recalled her trust in the healthcare team by saying:

> I felt that the information that they were giving me regarding him and his
> condition I trusted that they, being the professionals, knew what they
> were talking about because some of the things that they were telling me
> regarding his sickness I had already began to see in my brother. So the
> things that they told me I trusted what they said.

Family members were comforted in knowing HCPs were competent, and formed trusting relationships with HCPs as a result.

Perceived substandard or incompetent care. In contrast to recognizing HCPs as experts, family member also perceived HCPs as incompetent when they delivered substandard care. Family members sensed that decedents received substandard or incompetent care when HCPs made wrong diagnoses, medical errors (i.e., botched surgery), ignored decedents' calls for help, or neglected to care for decedent's physical needs (i.e., dirty bed linens and full colostomy bags). As a result of substandard or incompetent care, some family members reported that they were often anxious and

fearful about the care that decedents received. Several family members reported that substandard care altered their roles in decedents' care. Specifically, family members become more actively involved in decedents' care; vocally demanding that high quality care was given. Family Member 48 described this notion of active involvement by saying:

> There were times that I went there in the beginning when he began to soil his pants and soil his bed, and I'd go there and he would be wet, and of course I would pitch one and eventually having them come in to make sure they could be there at times that I wasn't there.

Quality of communication.

How communication with the healthcare team influenced decision-making. Aspects of helpful and poor communication are highlighted. Family members described how the content of HCPs' communication (i.e., information) influenced and shaped their perceptions of treatment options, outcomes, the severity of decedents' illnesses, and expectations of care. The manner in which HCPs delivered information was also important to family members, and influenced their decision-making. The overarching theme "Quality of Communication" included two subthemes: *Inadequate Communication and Openness and Honesty.*

Inadequate communication. Family members relied on HCPs as their primary sources of information regarding decedents' care. Family members received inadequate information from HCPs in various ways, including when HCPs did not share information with family members or include them in decision-making regarding decedents' care. Family Member 31, explained how he was not given information about his mother's care by saying, "They never really gave me options, just told me what they were going to do, this and that, this and that, and there was no options extended." He further explained how he did not participate in the decision for his mother to receive hospice care; in fact, he did not know she was receiving CFC. He stated, "They said oh, she's hospice, and

that's how I found out she was hospice. I didn't realize she was hospice before that." In

addition to neglecting to share information, HCPs who communicated overly optimistic

information regarding decedents' treatment options also gave family members

inadequate, and even misleading information. This type of communication frequently

resulted in family members' erroneous understanding of decedents' care and unrealistic

expectations of treatment outcomes.

Openness and honesty. In contrast to the detriment of receiving inadequate

information, family members found it helpful when HCPs communicated openly and

honestly. With open and honest communication, family members felt HCPs showed

care and were, therefore, more trusting of HCPs. Honest communication allowed

decedents, family members, and HCPs to have a shared understanding of decedents'

care. With open communication family members were better able to prepare for

decedents' deaths, because honest communication allowed them to form realistic

expectations of decedents' treatment outcomes. Family Member 25 recalled how honest

communication with HCPs helped her mother choose among treatment options, based

upon treatment outcomes. She stated:

> After thoroughly talking with the doctors, there was a team of doctors at
> both hospitals, and with her age, she was 79 years old, we knew that the
> convalescence was going to be very detrimental, as well as she simply
> did not want to have the surgery where they would go in and replace
> arteries and veins in different parts of her body. She didn't want that at
> all.

This decedent's HCPs were open and honest with her, which gave her the information

she needed in order to choose the most appropriate treatment, which for her, was CFC.

Aim 4. Describe African American bereaved family members' perceptions of the

decision to continue or discontinue life-prolonging treatment at the end-of-life.

For the purposes of this dissertation, an analytic decision was made by the

research team to discuss all sub-codes relevant to Aim 4, because no sub-code had

representation from at least one-third (five interviews) of the sample. A complete list of

codes and the coding dictionary are available in Appendix K. Major themes that

addressed aim 4 included, family members' perceptions of the decision to continue or

discontinue LPT.

   Decisions to Continue Life-Prolonging Treatment.

   Descriptions of family members' thoughts about life-prolonging treatment

and why they chose to use it or not. Family members were asked about their

thoughts regarding life-prolonging treatment and why they chose to use that type of

treatment near decedents' EOL. Family members' perceptions of the decision to

continue LPT varied. Reasons for continuing LPT included the following five subthemes:

Lack of Understanding, Unwilling to Give Up, Believe will Benefit, No Other Option

Given, and Patient Preferences for Life-prolonging Treatment.

   Lack of understanding. Several family members continued LPT because they did

not understand how sick decedents were. They received limited information from HCPs

regarding decedents' illnesses, along with mixed messages (i.e., HCPs offered LPT

alongside CFC), both of which contributed to family members' misunderstanding and

confusion regarding CFC.

   Unwilling to give up. On the other hand, some family members understood the

goals of CFC, however they felt CFC was inappropriate for their loved one. These family

members believed LPT was more suited to and congruent with their goal to prolong

decedents' lives. One family member (37) stated why she did not want to give up by

saying:

> I think because the family, the children and I didn't give up on him…We
> wasn't trying to just make him comfortable, just drug him up you know to
> make him comfortable. We are not in our heads think oh well he's about
> to pass like they was trying to put in our heads because we tried to get his
> strength up, you know, we wanted him to keep him giving him blood
> pressure medicine and his seizure medication or whatever other
> medication he needed. Where hospice care, they don't do all that. They

just make the patient comfortable and a lot of times they just drug them up. They stay in pain they just keep them drugged up.

Believe will benefit. In addition to unwillingness to give up, family members chose LPT because they believed this type treatment would benefit decedents. These beliefs were often due to an overestimation of decedents' odds of recovery. Also, since decedents had always received LPTs, family members believed continuing these treatments would maintain decedents' quality of life.

No other option given. While some family members felt that LPT would benefit decedent, others perceived LPT as the only choice available to them, based on communication with HCPs.

Patient preferences for life-prolonging treatment. Lastly, some family members chose to continue LPT because decedents wanted LPT, regardless of how frail their bodies had become. Family member 40 recalled her father's EOL wishes by saying, "I knew that he had said he wanted everything done to keep him alive."

Decisions to Discontinue Life-Prolonging Treatment.

Descriptions of family members' thoughts about comfort-focused care and why they chose to use it or not. Family members were asked about decisions to pursue CFC and why they chose to use this type of treatment near decedents' EOL. Several factors influenced decisions surrounding decedents receiving CFC, including the severity of decedents' illnesses, who made the decision to discontinue LPT (decedents, family members, or HCPs), where CFC took place (home versus institution), and decedents' and family members' desire for autonomy in decision-making. Family members' perceptions of the decision to discontinue LPT included the following eight subthemes: *Avoid Placement, Advice from Others, Conflict with Healthcare Providers, Healthcare Provider Decided, Just Happened (Not a Decision), Patient Preferences, Prevent Suffering, and Need Help-Overwhelmed.*

Avoid placement. Since family members and decedents desired the comfort of home over an institution, they opted to receive CFC in the home setting. At home, family members could provide care and decedents could be independent. It is important to note that HCPs' priorities of providing decedents with the most appropriate care (i.e., by a trained professional) sometimes contrasted decedents' and family members' desires for in-home care. In circumstances that did not allow decedents to receive CFC in the home, family members were willing to accept care in a facility, after they weighed the disadvantages and advantages of each location. Family members also considered decedents' care needs versus HCPs' recommendations.

Advice from others. HCPs' recommendation was another prominent reason family members chose CFC. Specifically, when HCPs explained the futility of LPTs, the benefits of CFC (i.e., gave decedents peace and comfort), and family members understood why CFC-related medical treatments were suitable for decedents' care, family members elected CFC. Information from HCPs elucidated family members' misconceptions and settled their concerns about CFC (i.e., removing feeding tube was killing decedent).

Conflict with healthcare providers. In contrast to accepting advice from HCPs, sometimes family members chose CFC due to conflicts with HCPs. Naturally, family members desired for HCPs to treat them civilly. What's more, they did not want to be belittled or bullied by HCPs. Additionally, family members desired a measure of autonomy and to work alongside HCPs in decedents' care. However, when conflict between family members and HCPs arose, HCPs' domineering behaviors precipitated family members' anger. In situations of conflict, family members evaded the offending HCPs by choosing alternative care plans and new HCPs with whom to work.

Healthcare provider decided. In other situations, HCPs took control of decedent's healthcare decision-making, regardless of family member's preferences. In

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these cases, the decision that decedents receive CFC seemed to be based on the severity of decedents' illnesses.

Just happened (not a decision). Similar to HCPs choosing CFC because of the severity of decedents' illnesses, sometimes decedents received CFC because their bodies were simply too fragile to continue LPT. Under these circumstances, decedents were transitioned to CFC because no other medical options were available. Additionally, some decedents received CFC due to family members' lack of knowledge regarding the type of treatment decedents were actually receiving. In these cases, family members were under the impression decedents were receiving LPT (i.e., rehabilitation), when they were actually receiving CFC.

Patient preferences. In some instances, decedents chose CFC to avoid painful LPTs, such as surgery; while others desired to stop LPTs, such as chemotherapy, to receive palliative care. One daughter (FM 35) recalled her mother's choice for CFC by saying, "Mama had requested…to end her life just the way she wanted to have it end."

Prevent suffering. Decedents and family members, alike, chose CFC to prevent suffering. This decision was often precipitated by decedents' extensive physical injury and family members' desires to stop decedents' suffering. Family members viewed suffering in several ways, including: 1) the decedents being in physical pain; 2) decedents' inability to enjoy activities s/he once had, such as eating; and 3) decedents' discomfort due to tubes in the body (i.e., feeding tube).

Need help – overwhelmed. Lastly, family members chose CFC in order to receive additional help as decedents neared death. Generally, decedents' care needs increased as death approached, yet family members desired to maintain a high standard of care in spite of having to provide more care. In order for decedent to receive the best, most reliable care, family members allowed hospice personnel to provide assistance in caring for decedents in their final days.

Table 16. African American Bereaved Family Members' Experiences of End-of-Life Decision-Making, Quality of Communication, Quality of Relationships with Healthcare Providers and Perceptions of the Decision to Continue or Discontinue Life-Prolonging Treatments at the End-of-Life

Theme	Sub-Theme	Exemplar Quotes
Understanding Understanding (and lack of understanding) about diagnosis, treatment outcomes, and end-of-life care options. Application of knowledge.	Diagnosis	Actually I knew quite a bit about it because I had dealt with it with a previous family member, so I kind of knew what to expect from it. It was livable at the time. I mean he could live with it you know, but he just him being him just wasn't complying with that lifestyle. – FM 17 At the time she was diagnosed I was in nursing school, so I knew a little bit more about it and I have an acute intuition. So when I found a lump in December, and it was firm and quite large to me. I knew she needed to get a mammogram, but mother is always been, well she doesn't like going to the doctor.so, I knew about it. I just didn't know that it would be stage 4. – FM 35
	Treatment Options	So really I wasn't given options as far as we can do this and we can do this. It was this is what we need to do. This is what we have to do to save her life and she still died anyway, so there wasn't a lot of options available. – FM 47 The doctor had informed us of what type of cancer he had which was at the time stage three non-small cell lung cancer. At the time the option was to do surgery and that was the very first thing that was an option for him when he first diagnosed. – FM 4
	Treatment Outcomes	The first part of her diagnosis, I was still in denial. I thought, oh she's going to get better. Because she was going to complete the chemo and the radiation. So she was staying with the program for quite a while, for at least less 6 months. So I was saying, oh she's going to come out of it." And all that, and of course she a big

Theme	Sub-Theme	Exemplar Quotes
		turnaround, because of course she was being treated.so she was talking better, she was eating better; she was getting back to - 3:50- but then, reality sunk in, probably at the later part of 2013 the early part of 2014. – FM 35
		At that point, at the last couple of weeks, we were at a no return. He had developed a bug or an infection that was at that point incurable. So speaking with them, they did everything that they possibly could. They tried all the medications, all the procedures. They did end up trying the dialysis, and it was just a little, a lot too late. – FM 17
	Changes in Condition	At first I thought he was doing fine, and then all at once he started getting weaker and sicker. He started losing his bowels. I thought he was doing better, but he wasn't, and then all of the sudden he wasn't responding. He was too weak. He had quit eating and anything, and he just had quit responding at all, and then about a week he passed. –FM 23
		The hospice peoples they prepared me for ... they had, I had already knew that he had, the doctors already said that he had maybe a month, no more than three months to live, and so I was prepared. The rest of the family they didn't believe them. I told them I did because he had started getting sick, he had started getting weak, and he got so he couldn't walk. – FM 23
	Prepared for Death	I was pretty much prepared. They had told me what to expect. I was pretty much prepared. At the end, I guess the end came so suddenly and I say suddenly because it was like one day he was laughing and talking and the next day he was in a semi coma, but I was prepared for him. – FM 48

Theme	Sub-Theme	Exemplar Quotes
		I was prepared because I communicated with his nurse and she let me know when there were changes in his breathing. I also because I was there 24/7 with my husband the last few weeks before he passed away I was able to report to her changes that I saw myself and she could tell me what I needed to do. She kept me aware of everything his nurse. – FM 4
	Unprepared for Death	It came as a surprise. It came as a surprise because there hadn't been any change in him. He had been basically the same. So it came very sudden, very sudden. – FM 40
		Well because they never really told us that it was that bad off to where they felt like that we should just not have him on any kind of tubes or anything like that because it was just… he never really gained any weight. It was more so of let's just wait and see if he gained any kind of weight. So at that point he couldn't keep anything down because he had very loose bowels, but he wasn't able to gain any weight because everything they was giving to him to put in that would give him any type of nutrition or gain any weight was basically coming back out with diarrhea. – FM 37
	Lack of Understanding	You know, as far as the term hospice, I don't know what the details of it are, but I know we had a couple people that would come over there, and they worked along the lines, -11:00-, they came over, checked on her, made sure she was all right, probably about three times a week, maybe four times a week. – FM 31
		I didn't understand about feeding tubes and removing them and what I see as starving somebody to death but I did a consultation with a couple of people. – FM 13

Theme	Sub-Theme	Exemplar Quotes
Relationship with Healthcare Team How relationship with the healthcare team influenced decision-making. Aspects of positive and negative relationships are highlighted.	Being Shown Care	I think we had an excellent relationship. We were kind, and they were kind. We respected their authority, and in return they gave us respect as a family. – FM 25
		I wouldn't say we were close. They were honest. They were straightforward. They were caring. They showed a lot of empathy, so much sympathy as empathy. They understood both sides. They did everything over and above and that's what I got from them. Even the smallest little thing as a warm blanket or more people in the room than should have been. They cared. – FM 17
	Available and Attentive	That they would call me just on the drop a dime and say what was going on and how he was feeling, whether if I was at work or at home, they would make sure that they called me and let me know what was going on. – FM 37
		I thought they ... well they appeared to be very attentive to my brother. They seemed to be concerned, and I appreciated that. Whenever I had questions or I needed to speak with one, if they were not available, I was able to, through the other staff and through the ministry part of the hospital they helped me out quite a bit as well. I was able to speak with the doctors and the various teams and they answered my questions. They were very professional, and I just really didn't have an issue with them at all. – FM 48
	Distrusting	Maybe after we realized that X couldn't walk, and he wasn't going to regain his ability to walk, a bit of distrust did creep in to the conversation. Why am I not able to walk now? They probably should have told me this before. Didn't they know that doing this

Theme	Sub-Theme	Exemplar Quotes
		around my spine would cause this right now, so it definitely came about after something as drastic as not being able to walk happened? - FM 26
		I feel like the hospital killed my mother. I do understand that she was sick, that there were going to be issues with her heart, but had the nurse not let her lay there with this blockage when she was throwing up, when she fell. She got up to walk and she fell, and he told her don't get out of bed anymore without me. My feet are cold. My feet are cold. He put two pair of footies on her. I'm in pain. I'm in pain. He gave her one dose of morphine. All from a cardiac cauterization. You as a nurse you're supposed to know the side effects of this procedure and that this is not normal and to investigate it more. I really just at some point I didn't even listen to the doctor. – FM 47
	Trusting	100% trusted, yes, that they knew what they were doing and it wasn't just the fact that, okay, this is just another hurry up and get it done and you know move onto the next step. They allowed you to trust them. They put it there for you know. Trust is a hard thing to do with strangers, and I didn't feel like they were strangers. I didn't feel like they were strangers at all, even though most of my contact with them in the beginning was over the telephone because I was in Georgia when he was, you know, so but they still no matter what time of day or night it was they called. They let me know. So I trusted everything that they were going to try to save him. – FM 17
		Oh, trust was there just based on the communication that we had from the very beginning. I felt like I could trust them because they were concerned about the care for my husband, not only for my husband but they were worried about me as well as being his wife and his caregiver. – FM 4

Theme	Sub-Theme	Exemplar Quotes
	Healthcare Provider Had Expertise	I think with their knowledge of a person's passing, the doctor was right to the point, even to the date, so that was really, really helpful for us, but like I said, when she came in, they took really good documentation along with the nurses and everything, but I felt like it was better for us to know up front than to be surprised, even with the foot. She told us how it would just literally die, and it did. She said you could look at it one hour, and the next hour it could be worse, and it was, so I really appreciated that. – FM 25
		I felt that I had to trust them because they were the, at the time, they were the caregivers. I felt that the information that they were giving me regarding him and his condition I trusted that they, being the professionals, knew what they were talking about because some of the things that they were telling me regarding his sickness I had already began to see in my brother. So the things that they told me I trusted what they said. – FM 48
	Perceived Substandard or Incompetent Care	It wasn't that great because of where we were. I felt we were there because of them. I didn't have a choice, but to put my trust in them because my mom was in their hospital, but I wasn't happy with them. I didn't even like to see them coming. I didn't like to hear them open their mouth because I just felt like the only thing they kept telling me was how sick my mom was. I knew she was sick, so I just kind of felt like that she didn't get ... I mean she was at Eskenazi. I just felt like she didn't get the best care possible because of the fact that they said she was already so sick. So if you're already so sick, what's the point in trying - 31:17 -? So if you live you live; if you die you die. I really just felt like that was their mentality. I don't feel like they did everything in their power to save my mother's life because there were too many mistakes on their part from her laying there right after that procedure like from the nurse to the doctors to the surgeons. I just don't feel like

Theme	Sub-Theme	Exemplar Quotes
		my mother's life was as important to them as it was to me and that they did everything in their power to save her life. – FM 47
		To know the difference of, I guess the difference between a seizure and, I don't know what it's called, where they have reflexes where they choke or whatever. There's a big difference. My father was having that issue, because I got off work, drove here to see him, and I noticed it. No one had checked on him for a period of time, and he was just sitting in the bed constantly shaking the whole time. I'm like oh-oh, daddy, what's wrong? I'm pushing this nurse button, he's like I done pushed it trying to call them, and nobody come to help me. Nobody come to help me and my thought would have been, by looking at this man's hands, or how weak he is in this state, it would be like maybe somebody going to check on somebody like every 20 minutes. If you know they can't push a button, that's what I'm saying. He was actually having seizures. They said oh, that's just a nervous reaction. No, because when the nurse came in the next morning, she checked and she said no, these are seizures. If they would have checked these two things, which I could have checked them when I saw her do it, I could have checked them, and that would have let me know right off, but you got a person, sitting in this state, shaking like this, and I know he was scared to death. I know he had to be, because I was, as much as he was shaking, as bad as he was shaking. I would have been scared to death, and there was nothing he could do, nothing I could do, and they said oh, that's just, they're just blowing it off like this is what this is. – FM 8
Quality of Communication How communication with the healthcare team influenced decision-making. Aspects of helpful	Inadequate Communication	When I first found out and went over to check on her, one time nobody was in the room, and I told them, what is this, and they said oh, she's hospice, and that's how I found out she was hospice. I didn't realize she was hospice before that. They moved her room, and they had to look it up and they found out she was hospice,

Theme	Sub-Theme	Exemplar Quotes
and poor communication are highlighted.		and I realized that's what she was. When she initially went in, nobody told us and I'm thinking therapy, some therapy and treatment that she may be able to get out, but when she went in the hospital, she went to the nursing home and she stayed there those two years, before she passed. – FM 31
		Yeah, that would be it, the communication part, explaining what's next, things like that. What to look for. You're going to be here, this is what you need to look for, and then I guess letting us know. If you want somebody to come in certain hours, because you know any type of rehabilitation place or place like that, they can't do a lot of stuff. They can't do a lot of stuff. I guess it would help if they had an extra number to give the caretakers, the people that's going to be there all the time, say okay, if you want somebody that could come in and sit with your father for about maybe three or four hours during the night, if you're at work, you know what I'm saying, something like that, that would have helped me also. –FM 8
	Openness and Honesty	As far as, like I said, their honesty that was helpful. The fact that they didn't how do you say sugar coat anything. This is what's happening. This is what we can try. We're not telling you that it's not going to work, but we're not also telling you that it's going to work, but we're going to give it our best shot. So their honesty really did help out a lot. – FM 17
		Other than that, the social worker was nice. Doctor was nice. She was straight to the point with me. She didn't hem-haw around. Nobody likes that, just being straightforward. The nursing staff and the CNA, the nurse's assistants, whatever they're called. They were fantastic. – FM 25

Theme	Sub-Theme	Exemplar Quotes
Decisions to Continue Life-Prolonging Treatment	Lack of Understanding	That choice had been given to us in the very beginning for hospice and we declined it not really knowing what hospice was. – FM 4
Family members' thoughts about life-prolonging treatment and why they chose to use it or not.		In fact, they never really said it was that deep. At that point no. Yes, I had no idea. They just said it was congestive heart failure but not only just congestive heart failure because that could have been dealt with, it was more so his liver and everyone like that couldn't hold up. They was trying to work on his liver and give him some nutrients and stuff to try to get his weight up. – FM 37
	Unwilling to Give Up	Yes, that's what I think because the family, the children and I didn't give up on him, you know what I'm saying in a sense that we didn't want him resuscitated. We didn't want him still getting - 23:50 -. I'm trying to think of the word, evaluated by doctors, you know that we wanted to prepare him for being able to come back home, you know. We wasn't trying to just make him comfortable, just drug him up you know to make him comfortable. We are not in our heads think oh well he's about to pass like they was trying to put in our heads because we tried to get his strength up, you know, we wanted him to keep him giving him blood pressure medicine and his seizure medication or whatever other medication he needed. Where hospice care, they don't do all that. They just make the patient comfortable and a lot of times they just drug them up. They stay in pain they just keep them drugged up. – FM 39
	Believe Will Benefit	So really I wasn't given options as far as we can do this and we can do this. It was this is what we need to do. This is what we have to do to save her life and she still died anyway, so there wasn't a lot of options available. Does that make sense? - FM 47
		In the beginning when hospice was first brought to our attention our thoughts were we didn't want hospice because my theory was

Theme	Sub-Theme	Exemplar Quotes
		always hospice is the last thing before you die. That means you only have six months to live. I was optimistic. I thought that he would be able to be healed because he had cancer before and he was. So when they told us we're offering hospice if you would like to accept it and we were like, no, he doesn't need hospice. No. That's for people that's going to die. We didn't take it then. – FM 4
	No Other Option Given	He just had CareWatch - come in and just watch him over night. – FM 37
	Patient Preferences for Life-Prolonging Treatment	He was at the hospital and he coded and that's when they put him on life support, and he was on life support and I know they were doing everything they could to keep him alive. This was prior to him coming home. He was on life support for a while and then he had told us that he wanted them to do all that they could to keep him alive and that's what he shared with the family; that he wanted everything to be done to keep him alive and so that's what we did. – FM 40
		My mom did have periods of where she was coming out of unconsciousness. She would have her eyes open and could answer like, mom, are you in pain? She would shake her head no or yes. I'm like, mom, do you want to live? Yes. She would shake her head yes. You could ask her questions and she could shake yes or no. – FM 47
Decisions to Discontinue Life-Prolonging Treatment	Avoid placement	Yes, that was discussed. Yeah, they were wanting to put him into a nursing home, because they didn't think he could take care of himself, and he had a family member staying with him that volunteered to do that, but they thought that he needed more care than someone that wasn't trained could provide. He refused. He

Theme	Sub-Theme	Exemplar Quotes
Family members' thoughts about comfort-focused care and why they chose to use it or not.		wanted to be home, and coming down to, I don't think I heard anything about hospice until maybe about two weeks before he passed. He didn't want to go there or do any of that. – FM 26
		What I am saying is there were two times that this was not hospice. I don't know what, there were some other health care people that were being called in but somebody raised the questions about her going into the nursing home and we were saying there was no way. She had to die at home. That had been my thought that is how it would have ended up but I was pleased that she did, in fact, go to the hospital and that it did go the way it ended up. – FM 13
	Advice from others	They said hospice and I just went along with them that they said, they said hospice would come to the house. I told them I didn't want to put him in no place. – FM 23
		Well my thoughts I had…Well, I can tell you that again what helped me with all of that was my cousin the nun who explained to me about how a lot of the nuns were taken off of the feeding tube. I mean I had a better understanding of it and it wasn't like I was killing my sister. It actually was a natural way to go. I mean that was of some concern, you feel like you are participating in killing her and with having those discussions with her especially I looked at it differently and that it was a natural way for her to go. – FM 13

Theme	Sub-Theme	Exemplar Quotes
	Conflict with Healthcare Providers	The reason I let hospice take over completely, the nurse from Dr. X's office she came to the house and she ... she tried to get smart. She going to tell me that Dr. X could take X and put him in a nursing home. I told her, no, she wasn't. She said, well, Dr. X had power. I said, well, if Dr. X had all that power why didn't she know that he had lung and brain cancer and so ... and I asked the nurse and the nurse told me she said ... see it was a nurse. She had to report everything that went on in this house to Dr. X's office. So one day she came here and I had washed down the bed, but it was a pad and then the bed was wet, but I explained to the nurse that I washed it down that he wasn't wet or anything. So that's when that social worker came out here and she tried to get smart, and I told her I didn't have to put up with her. So I called Dr. X's office, and I told them I no longer wanted Dr. X's service. So the nurse asked me she said do you want us to take over? I told her yes. She said because she wouldn't have to report anything to Dr. X. So they took over completely. – FM 23
	Healthcare Provider Decided	The treatment option is kind of like what I was just stating. The last month when he went back to the hospital when he was septic and had a stay there, it was a lady doctor. She was the only one in the room that had called the family, and they told us that they wanted to remove the tubes, the vent tubes, and she said they was gonna… if he couldn't breath on his own, then we're going to put him back on it and basically she said like if he coded again that they wanted to put him on the DO NOT RESUSCITATE. – FM 39
	Just happened (not a decision)	Yes. Yes. They said that they would do whatever they could to make him comfortable. The last time they said they was doing all they could to make him comfortable, but basically they was just making

Theme	Sub-Theme	Exemplar Quotes
		him comfortable because there was nothing else they could do because they could not get his blood pressure to go up. – FM 40
		Yeah because I was there like the night before and they had a guy come in and at this time they had kind of like undid all his tubes to see if he would be able to kind of breath on his own, which he would; just to see how his progression would go without anything without them giving him any kind of oxygen or anything. So when I left that night he was fine. They kind of played music for him. He knew the music that they were playing, but I didn't think when they checking on him throughout the night and they see that things were beginning to be worse, like his breathing probably wasn't as strong as it was before, you know, the night or that morning and they could tell that his oxygen level was going down. I feel like that they could have been able to call us then and say well his oxygen level is decreasing. I don't know if he'll make it to the end of the morning because they're checking on him, he's right there, and they're checking on him all night long, so I feel like they knew at this point that, you know, it was just he was going to stop eventually. – FM 37
	Patient preferences	At that point, she stopped doing chemo and radiation; actually, she enrolled into the hospice program. So they was pretty much doing the palliative care, which was going exceptionally well because, mama had requested just the shot and to end her life just the way she wanted to have it end, ended. All the way up until the end. So, I was fine with that, she actually looked better to me. – FM 35
		After thoroughly talking with the doctors, there was a team of doctors at both hospitals, and with her age, she was 79 years old, we knew that the convalescence was going to be very detrimental, as well as she simply did not want to have the surgery where they

Theme	Sub-Theme	Exemplar Quotes
		would go in and replace arteries and veins in different parts of her body. She didn't want that at all. – FM 25
	Prevent suffering	Actually she was at peace with it. She told me about two to three weeks before the doctor even said that, she was at peace with it, and she herself after going through hospice with several of her children and parents and things, she pretty much knew what the outcome would be, so she pretty much prepared us as we went along, on when to start inducing the end of life care, because she did not want to suffer, so when she felt like the suffering was more than what she could bear, because she really suffered with the leg pain and all of that, so she pretty much told us when to start the end of life care. – FM 25
		Then she coded. She coughed and caught it in the trach again and coded again. By then they were telling me we've got to have a surgery. We've got to get the trach out and put her back on the vent. This is not working. The second time she coded that day she had brain damage and from there I gave the do not resuscitate order. I held my mother's hand until she died that night because she pretty much had brain damage. – FM 47
	Need Help - Overwhelmed	I mean they was helpful because I don't think I could have made it without them. Because they had asked me did I want them here at his last times, but I didn't think he was dying that week. They asked me did I want any of them here with me, and at first I told them no. Then after it got so bad and I told them yes. – FM 23
		You know the main reason I called Hospice was X had been there for over 24 years and I knew she was struggling. You know I am here 400 miles away dealing with issues over the phone. I wasn't there from day to day to see my sister go to hell and all of that, so somebody told me, I guess my minister or somebody here to call

Theme	Sub-Theme	Exemplar Quotes
		hospice. It was really for X, just to get some support for her and that really was helpful because being there with the nurses coming in or health care people coming in and so I just felt that there was some assistance that was being provided for X. And I know that it was of some benefit I believe for my sister relative to whatever they do, the pain stops and making her comfortable. – FM 13

Summary

The quantitative (Aims 1 & 2) and qualitative (Aims 3 & 4) findings will be discussed separately. The primary quantitative findings included observation of significant relationships between family members' quality of communication with HCPs and decisional conflict. Family members' general (p = .000) and EOL (p = .003) communication scores were negatively correlated with their decisional conflict scores. Family members' reports of higher quality of general (p =.030) and EOL (p = .014) communication significantly predicted lower decisional conflict scores. Lastly, decision regret scores were significantly higher (p = .030) among family members whose loved one received LPT versus those whose loved one received CFC.

This study also revealed several important findings related to relationships among family members' quality of communication, decision outcomes, decedents' characteristics, and family members' characteristics. Family members of female decedents reported higher general (p = .013) and EOL (p = .033) communication scores than family members of male decedents. Higher ratings of quality of general (p = .043) and EOL communication (p = .030) were positively correlated with family member age. Family members' EOL communication scores also were positively correlated with the decedent's age (p = .028). Family members' quality of general communication was positively correlated with religious values scores (p = .026). Family members' decisional conflict scores were negatively correlated with religious values scores (p = .047). Lastly, being the family member of a male decedent significantly predicted decision regret scores (p = .022).

Qualitative themes related to AA family members' experiences in EOL decision-making included Understanding, Relationship with the Healthcare Team, and the Quality of Communication between family members and HCPs. Major themes related to family members' reasons for continuing LPT included Unwilling to Give Up, Believe Will

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Benefit, No Other Option Given, and Patient Preferences for Life-Prolonging Treatment. Qualitative themes related to family members' reasons for discontinuing LPT included Avoid Placement, Advice From Others, Conflict with Healthcare Providers, Healthcare Provider Decided, Just Happened (Not a Decision), Patient Preferences, Prevent Suffering, and Need Help-Overwhelmed. Surprisingly, religious values and cultural values did not emerge as major themes in relation to family members' EOL decision-making. In fact, religious values and cultural values were seldom spontaneously mentioned during qualitative interviews.

<center>**Chapter Five**</center>

This chapter includes a brief overview of the major findings in the context of existing literature, limitations, implications for future research, and conclusions.

<center>**Discussion of Important Findings**</center>

Discussion of Quantitative Findings

To the investigator's knowledge, this is the only study to examine decisional conflict within the context of end-of-life (EOL) decision-making for bereaved AA family members of AAs who died with a serious illness. Study findings revealed that family members' quality general and EOL communication were negatively correlated with decisional conflict. Additionally, family members' quality of general and EOL communication were significant predictors of decisional conflict. These findings suggest that when AA bereaved family members experience poor quality of general and EOL communication with healthcare providers (HCP), family members feel more uncertain about EOL decisions.

Several other studies have found that negative associations between decisional conflict and patients' knowledge, satisfaction with information, and shared decision-making exist[221,294,295]; however, this study's focus on the relationship between decisional conflict and the quality of communication is unique. Overwhelming evidence suggests that decision-making and decisional conflict for patients with serious illnesses and their families are impacted by several factors. These factors include knowledge about diagnosis, treatment options, and treatment outcomes, as well as information received from HCPs[221,294-298]. The findings of this dissertation study corroborate the findings of other studies, and adds new knowledge that directly links decisional conflict to quality of communication.

Establishing a link between quality of communication and decisional conflict is important because it may represent a first step in a line of research that ultimately will

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lead to interventions to enhance communication and decision outcomes at EOL for AAs and their families. The findings of this dissertation study are relevant because communication is a critical component of EOL decision-making among AAs and their families[299]. Good patient-family member-provider communication that relays adequate information has the potential to bolster patients' and family members' understanding, and is necessary for shared decision-making[300-306]. When HCPs do not deliver adequate information pertaining to diagnosis, treatment options, and treatment outcomes, patients and family members are less likely to participate in shared decision-making, and more likely to lack knowledge, report uncertainty, and experience high decisional conflict[221,294,297,298,307].

Evidence suggests that AAs lack knowledge of life-prolonging treatments (LPT), often do not seek knowledge, or do not know how to seek knowledge regarding LPT[101,341,342]. However, when given adequate information about EOL care options, AAs have chosen LPT less often and experienced less decisional conflict[221,308]. This information is significant because it suggests that decisional conflict is a modifiable construct. This dissertation study's findings indicate that quality of general and EOL communication predict decisional conflict. Since AAs' decisional conflict has been reduced by giving adequate information in previous studies, plausibly, quality of communication can be modified to reduce decisional conflict as well.

Another significant finding of this study revealed that family members experienced more decision regret about decisions to continue LPT than decisions to discontinue. This finding is consistent with the findings of other studies. Evidence suggests that do-not-resuscitate orders predicted better mental health for family members[309]. Additionally, bereaved caregivers' quality of life has been positively associated with comfort-focused care (CFC) and negatively associated with regret[310]. Other studies have demonstrated that bereaved family members had less regret when

they were able to care for decedents directly and when decedents died peacefully.[311] Furthermore, evidence suggests that better quality of patients' deaths reduced the risk of regret, as well as improved quality of life for bereaved family members[309]. This dissertation study's findings, along with that of other studies suggest that family members of decedents who received CFC were better able to accept their EOL care decisions. Conversely, the family members of decedents who continued LPT were more likely to regret these decisions.

A plausible explanation for this dissertation study's findings may lie in the quality of EOL communication family members received from HCPs regarding CFC versus LPT. This study indicated that although the quality of EOL communication did not significantly differ between family members of decedents who received CFC versus those who received LPT, the mean difference did approach significance. It is reasonable to suspect that family members of decedents who received CFC had less regret because they made choices based on better communication with HCPs than family members of decedents who received LPT.

As mentioned previously, when AAs receive adequate information from HCPs regarding EOL care options, they are more likely to choose CFC[221]. Additionally, evidence suggests that HCPs often have ineffective EOL communication with family members. Indeed, family members have reported that HCPs did not inform them that decedents' diseases were incurable, did not provide life expectancy, and did not discuss using hospice[312]. To add, other investigators have found that family members wished HCPs had better prepared them for decedents' deaths[312-314]. This study's finding that family members of decedents who had used LPT had higher levels of regret can reasonably be explained by the quality of EOL communication that family members perceived they had with HCPs.

Another interesting finding of this study revealed that decedents' gender predicted family members' decision regret. Specifically, family members of male decedents had higher decision regret than family members of female decedents. The investigator found no other study that associated gender with decision regret. The difference in family members' decision regret by decedent gender may be explained by secondary findings of this study. Secondary findings showed that family members of female decedents reported higher quality of general and EOL communication than those of male decedents.

This finding echoes the findings of another study, which indicated that family members of male decedents were less satisfied with information and communication than those of female decedents[315]. These investigators offered no explanation for the gender difference in family members' quality of communication. Given the findings of this dissertation study, a reasonable explanation may be that male decedents were sicker or entered the healthcare system with later-stage diagnoses than their female decedent counterparts. Entering the healthcare system with more severe illnesses may have worsened family member-provider communication, if decedents' deaths occurred quickly after diagnoses.

This explanation is plausible because studies have found that elderly women use healthcare more often than men[233] and women are, generally, more proactive at maintaining their health than men[316]. Furthermore, men are more likely to have serious illnesses associated with higher mortality rates, such as coronary artery disease, diabetes, chronic kidney disease, and chronic obstructive pulmonary disease. What's more, men suffer from significantly higher illness severity, comorbidities, and in-hospital mortality rates than women.[317] Women, on the other hand, suffer from less serious illnesses such depression, osteoporosis, and hypertension[317].

Concerning communication, research suggests that family members experience poor EOL communication and make poor decisions, especially when decedents are near death. These poor decisions are frequently made in emergency situations, when family members do not have the information or time to completely understand the consequences of their decisions[318,319]. To add, one study found that women whose husbands died quickly (i.e., 24-hours to one week) after they were informed of a terminal diagnosis reported poor communication, bitterness about the care that was provided, and were unprepared for their husbands' deaths [319]. Hence, the gender difference in quality of communication is plausibly the result of men who presented to the healthcare system with late-stage diagnoses. This, in turn, may reasonably explain the gender difference in family members' decision regret.

An alternative explanation for family members' of male decedents higher decision regret may be related to the decedents' age. Post-hoc analysis revealed that male decedents in this study were, on average, younger than female decedents. This explanation is supported by other secondary findings of this study, which indicate that family members' quality of EOL communication with HCPs was positively correlated with family members' ages and decedents' ages. This study's finding that older family members had higher quality of EOL communication for older decedents is substantiated by the findings of another study whose investigators found that family members of the oldest patients were more satisfied with aspects of care related to family member-provider communication[320].

Younger caregivers are more likely to have difficulties in EOL decision-making than are older caregivers[321]. Specifically, the younger a caregiver's age, the more difficult are his/her decisions on decedent's place of care, do-not-resuscitate order, and whether to continue or discontinue LPTs[321]. Younger caregivers' difficulties in decision-making may be explained by the age of the decedent. Evidence indicates that family

members of younger patients have increased risk of poor comprehension of information regarding patients' diagnoses, prognoses, and treatment options[322]. These findings suggest that, perhaps, family members of older patients are better able to accept that older patients have life-limiting illnesses[323]. Because the average age of decedents in this dissertation study was nearly 69 years old, and male decedents were typically younger than female decedents, perhaps family members were more comfortable making EOL decisions for older female decedents, because they experienced better EOL communication with HCPs. The findings of this and other studies lends evidence to explain why family members had more decision regret for male decedents and poorer quality of communication for younger decedents.

Other interesting findings of this study showed that family members' religious values were positively correlated with quality of general communication with HCPs and negatively correlated with decisional conflict. The former finding is consistent with one other where AAs' quality of communication was positively associated with religious beliefs[296]. In addition to measuring religious beliefs and quality of communication, these investigators also measured AAs' trust in HCPs, and found that AAs' trust in HCPs was negatively associated with their quality of communication with HCPs[296].

Evidence suggests that stronger religious values have been associated with greater trust in HCPs; trust, in turn, has been associated with higher quality of communication with HCPs. Conversely, distrust in HCPs has been associated with poorer quality of patient-provider relationship and communication[296,324]. These findings are vital, especially within the context of AAs with serious illness and their families, because AAs often use religious beliefs to cope with illnesses[325]. Other studies have shown that patients who regularly attend religious services are more likely to trust and have more confidence in their HCPs[325]. Furthermore, when AAs perceive that HCPs

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respect their religious beliefs, or even disclose their own religious beliefs, AAs are more trusting of those HCPs[299].

In this dissertation study, the positive association between family members' religious values and quality of communication may have occurred because most of the family members held strong religious beliefs. More than 95% of the family members in this study reported a Christian religious affiliation, and many scored highly on the Religious Beliefs and Values Scale. Family members' strong religious beliefs may have contributed to their trust in HCPs which, in turn, improved the quality of communication they had with HCPs. Family members' improved quality of communication, plausibly, contributed to their reports of less decisional conflict. This study adds new information regarding the relationship between religious beliefs and family member-provider communication, which has been understudied[95]. It also establishes a possible connection between religious values, quality of communication, and decisional conflict.

To the investigator's knowledge, this is the only study to combine quantitative and qualitative methods to assess AA bereaved family members' quality of communication with HCPs. This study also contributes additional evidence to our mounting knowledge regarding the need for improved communication between AAs and HCPs during EOL care encounters. The study's quantitative findings related to quality of communication and decisional conflict were consistent with the qualitative findings regarding family members' reports of quality of communication with HCPs and uncertainty in decision-making. Specifically, this consistency indicates that family members who reported lower quality of communication were also more likely to have had moderate to high decisional conflict, as suggested by multivariable logistic regression analyses. Family members' reports of poor quality of communication with resultant uncertain decision-making are described numerous times throughout the qualitative section that follows.

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Discussion of Qualitative Findings

Qualitative themes related to AA family members' experiences in EOL decision-making included Understanding, Relationships with the Healthcare Team, and Quality of Communication. Communication was a prominent topic that weaved through all three themes. Family members described their experiences of problematic communication, which were often centered on the decedents' diagnoses, treatment options, treatment outcomes, and expectations as decedents neared death. Problematic communication occurred in encounters when HCPs treated family members uncivilly or spoke too optimistically regarding treatment outcomes. Furthermore, family members reported that inadequate or limited information was a detriment to their understanding and decision-making. Specifically, the content of HCPs' communication (i.e., information) drove family members' decision-making because it helped (or hindered) their understanding of decedents' treatment options and outcomes, the severity of family members' illnesses, and what to expect as decedents neared death.

The qualitative findings of this study are consistent with those of other studies which suggest AA often have poor communication with HCPs[210,299,326,327]. Other studies have shown AAs experience poor, verbally dominant communication and receive inadequate information during encounters with HCPs[102,210,326,328]. Findings from this dissertation study are also consistent with the findings of another study whose investigators found that family members who did not receive information alerting them of the severity of decedents' illnesses were more likely to feel surprised by and unprepared for decedents' deaths[319].

As a result of poor communication with HCPs, family members in the dissertation study reported limited understanding of diagnoses, treatment options, and/or treatment outcomes, conveyed more uncertainty in decision-making, and expressed desires for more information from HCPs. Additionally, family members described dissatisfaction

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with care outcomes and wished they had made different decisions. These qualitative findings are consistent with the findings of other studies that also found poor communication was associated with limited understanding, uncertainty, and decision regret[271,299,329,330].

In addition to problematic communication, family members also experienced helpful communication with HCPs. For instance, family members reported it was helpful that HCPs be open and honest in their communication, as well as provide all pertinent information regarding decedents' care in a straightforward manner. In addition to open communication, family members wanted to be involved in discussions about decedents' care and share in decision-making. These findings are consistent with the findings of several other studies whose investigators revealed that family members desired open communication and to participate in decision-making[95,98,102,299,331,332].

Another major qualitative theme of this study was the importance of family members' relationships with healthcare teams. Family members' relationships with HCPs were established with informative and open communication, high quality and competent healthcare, mutual respect, empathy, and kindness. Additionally, family members' relationships with HCPs were based on HCPs' availability to converse about decedents' care, HCPs' attentiveness to decedent's care needs, and family members' trust in HCPs. HCPs garnered family members' trust by communicating openly, providing adequate information, engaging in unhurried interactions, and giving competent, expert care.

Only one other study was found that assessed bereaved AA family members' experiences of communicating with HCPs regarding a loved one's EOL care. This other study's findings echoed several of this dissertation study's findings[102]. Specifically, both studies found that AA bereaved family members desired to have open communication, be treated with respect and kindness, and be kept informed of decedents' care[102]. Other

studies reported findings consistent with this dissertation study's findings, however these other studies were conducted in different contexts of care. Nevertheless, these studies found that patients desired to have open and honest communication with HCPs, which was complemented by empathy and respect from HCPs[299,318]. This dissertation study is consistent with existing literature regarding bereaved AA family members' communication with HCPs. However, this study contributes novel knowledge that is specific to the relationships that bereaved AA family members had with HCPs within the context of EOL decision-making for loved ones with serious illnesses.

Several themes emerged regarding family members' perceptions of the choice to continue LPTs, including Lack of Understanding, Unwilling to Give Up, Believe Will Benefit, No Other Option Given, and Patient Preferences for Life-Prolonging Treatment. Within these themes, family members often described how communication contributed to their decision-making. Some decedents received LPT because this was the only treatment choice presented to family members. Similarly, other decedents received LPT because family members were given limited information from HCPs regarding the severity of decedents' illnesses and the treatments that were most appropriate for those illnesses. To a lesser extent, decedents' preferences for LPT influenced EOL decision-making. In fact, only two of 15 decedents received LPT because it was their preference. In addition to the two decedents who preferred LPT, only one decedent received LPT due to family member's preference.

The findings of this dissertation study contrasts a large body of research suggesting AAs prefer LPT to CFC[204,308,333-335]. Additionally, this study contradicts another study that found that AAs who desired CFC, still received LPTs, regardless of their EOL care preferences[202]. In this dissertation study, decedents who desired CFC also received CFC. This dissertation study contributes more evidence that patients and family members experience poor communication with HCPs at EOL, challenges the

majority of the literature that suggests AAs desire LPTs, and lends support to a small, but growing, number of studies that found AAs prefer CFC at EOL when they are given adequate information[221,308].

Several themes emerged to explain why family members chose to use CFC. These themes included: Family Members Received Advice from Others; Needed Help to Care for Decedents; Wanted to Prevent Decedents' Suffering; Wanted to Avoid Placing Decedents into Care Facilities (i.e., nursing home); and Honored Decedents' Preferences for CFC. To a lesser extent, decedents received CFC because No Treatment Choice Was Made. Communication played a prominent role in the reasons that family members chose CFC. It was the information-rich guidance received from HCPs that helped several family members understand the futility of LPTs and the benefits of CFC (i.e., comfort for decedents). What's more, communication with HCPs helped family members understand the care options that CFC offered. For example, the option of decedents receiving CFC in-home rather than in a facility (i.e., a nursing home). Furthermore, information from HCPs dispelled family member's misconceptions about CFC; for instance, the idea that removing a feeding tube equated to "killing" the decedent.

Ironically, poor communication with HCPs also led family members to choose CFC. Specifically, HCPs who delivered LPTs and were verbally dominant swayed family members to seek alternative treatments (i.e., CFC) and new HCPs (i.e., hospice personnel) in order to avoid contact with the offending providers. These findings are consistent with those of several other studies that suggest the manner in which HCPs deliver communication and information influences family members' EOL care decisions[102,299,321].

In addition to communication, a second significant theme that family members discussed was their desire to prevent decedents from suffering. This theme emerged

even when family members were not asked questions regarding decedents' suffering. Additionally, decedents, themselves, often preferred CFC to LPT. Several decedents signed do-not-resuscitate orders or explicitly expressed that they did not want to suffer as they died. These finding are consistent with those of another study whose investigators identified several factors that family members and patients believed constituted a "good death". Among these factors was pain and symptom management. Several patients and family member emphasized their desires that decedents not suffer[336].

Lastly, a small number of decedents received CFC because HCPs chose CFC or because there was no decision made (i.e., CFC just happened). Both of these circumstances were predicated on the severity of decedents' illnesses. Specifically, decedents were so critically ill that there were no medical options available beyond comfort measures. The findings of this study are consistent with those of another study, which showed AA bereaved family members wanted decedents to be comfortable in death, without suffering[102]. The findings of this dissertation study broaden our understanding of AA preferences for EOL treatments by giving reasons why AAs chose CFC over LPT.

Often it is important to consider nonsignificant results when evaluating study findings. In this study, no significant relationships were found among family members' religious affiliation and EOL treatment decision or decision outcomes. Furthermore, in qualitative interviews family members did not spontaneously mention that religious values or cultural values played a role in their EOL decision-making. These were not discussed in the results or discussion sections because family members simply did not talk about them. The fact that AA family members did not mention religious values or cultural values in the context of EOL decision-making is especially interesting, because

these variables are often cited as central to AA decision-making, especially at EOL[34,87,337-339].

Limitations

Several limitations should be noted when interpreting the results of this study. One important limitation was the small sample size. Since research is limited in this area, there was no statistical basis to approximate the sample size needed. The study enrolled 49 bereaved family members for several reasons. First, a sample size of 49 allowed for good estimates of reliability of the Ottawa Decision Support (ODS), Religious Beliefs and Values, and Quality of Communication instruments. Although all study measures performed well in this sample, results from each should be interpreted cautiously. The results of regression analysis with a small sample should also be carefully evaluated. In order to minimize this limitation, the number of covariates entered in multivariable logistic regressions was limited to two; and for multivariable linear regressions, the number of covariates was not more than three.

Although study findings generated valuable new knowledge from a subset of 15 interviews, data saturation was not achieved. Therefore, future work will use the full dataset (n = 50) to identify the complex and subtle connections among variables. Additionally, the goal of the qualitative portion this study was to produce rich descriptions of AAs' experiences within the context of EOL decision-making for a loved one with serious illness. These rich descriptions of AAs EOL experiences may be transferable to identify elements of the experiences of other AAs making EOL decisions in various other settings. However, these findings may not be generalizable beyond the AAs in this study, because there is no way of knowing if the findings that emerged from 15 interviews represent the typical experiences of all bereaved AA family members[340].

Another limitation of this study was the potential for selection bias. Ninety percent of the sample was recruited from Eskenazi's Palliative Care Program. Family

members who received consultation from the Eskenazi Palliative Care Program may have received information and guidance regarding decedents' care which influenced their decision-making. This may not reflect the experiences of AA family members who are never exposed to or receive information from the healthcare system, particularly a palliative care consultation program. Hence, this study's sample may not represent the average population of AA family members of AAs with serious illnesses and generalizability may be limited to those in Eskenazi's Palliative Care Program or similar healthcare settings. This study also enrolled a small number of bereaved AA family members from Eastern Star Church, a large metropolitan church, in the Indianapolis community. Participants from Eastern Star Church may be more representative of AAs in the community who had not received care from a healthcare institution. However, they represented only 10% of the study's sample.

Other limitations result from the study's design. Since this was a retrospective cross-sectional study, which captured data at one single point in time, no causality can be inferred. Additionally, since the investigator conducted telephone interviews two to six months after decedents had died, family members' perceptions of communication with HCPs may have changed over time. Specifically, through the passing of time, family members may have formed overly negative or positive perceptions of HCPs' communication patterns. Furthermore, data were collected over the telephone. Therefore, qualitative data may not have been as rich as it might have been if interviews were conducted in-person. Face-to-face interviews may have been a more appropriate method for gathering qualitative data about a sensitive topic such as the death of a loved one.

The study's eligibility criteria may be another limitation. To be eligible, AA bereaved family members had to speak and read English and have a telephone. This excluded participants without telephones and those with language or reading barriers.

Finally, bereaved AA family members provided the data for this study. Evidence has shown family members' reports of decedents' observable symptoms have been congruent with decedent reports[341,342]. However, the investigator in this study asked family members to report on their experiences in EOL decision-making, communication with HCPs, relationships with HCPs, and the decision to continue or discontinue LPTs. Family members did, indeed, report decedents' physical symptoms, but also reported on their own perceptions of their and decedents' quality of communication, relationship with HCPs, and why decedents received LPT or CFC. The accuracy of their recall of decedents' perceptions and experiences was not able to be verified.

Implications for Future Research

To the investigator's knowledge, this is the only study to: 1) quantitatively measure the quality of communication, decision regret, and decisional conflict of bereaved AA family members; and 2) qualitatively describe bereaved AA family members' relationships with HCPs. The findings of this study have provided invaluable new knowledge regarding AAs family members' quality of communication, decision outcomes, and relationships with HCPs at EOL. Although EOL care research has been prioritized in recent years, it is still a relatively new field of study[2], so the findings of this study have important implications to advance EOL care, decision-making, and nursing research.

The findings of this study have shown that quality of communication with HCPs is an integral component of family-centered care, especially at EOL. There is limited research exploring communication between AA family members and the healthcare team. Indeed, most EOL communication research has focused on experiences between patients and HCPs, which emphasize the patient-provider relationship[343-347]. In order to develop effective interventions that are tailored to the specific needs of AAs with serious

illnesses and their families, more descriptive and prospective research focused on AA

family members' involvement in healthcare decision-making is essential.

Valid and reliable measures exist, and have been used to assess some aspects

of the EOL care experience, mainly among individuals with cancer. However, these

measures have not been tested within diverse racial, ethnic, age, or cultural groups[2].

This study used several measures, including the Religious Beliefs and Values, Quality of

Communication, Decision Regret, and Decisional Conflict Scales among AA bereaved

family members of decedent who died with various serious illnesses, which included

cancer. These measures performed well in this study sample of AA family members and

contributed valuable knowledge concerning religious beliefs, communication, and

decision outcomes.

Major research organizations have called for development of conceptual models

and frameworks to guide research in EOL care[2]. The investigator used the Ottawa

Decision Support Framework and the literature to guide this study. The investigator-

developed African American End-of-life Decision-making Conceptual Framework was

also used to guide this study. The findings of this foundational study provide a starting

point to guide future research, with the long-term goal of developing interventions to

improve EOL care for AAs and their families.

Given that the majority of studies, including the current study, have had a cross-

sectional descriptive design, these studies did not capture data beyond a single point in

time. Gathering information at disease diagnosis, CFC recommendation, and during

family members' bereavement would give us a better understanding of the decision-

making process as it evolves over the care continuum. This is especially important in

the context of EOL care, because EOL decision-making does not constitute one

decision, but a series of decisions made over time.

Hence, there are two logical next steps in this line of research. First, a future research study should test the Religious Beliefs and Values, Quality of Communication, Decision Regret, and Decisional Conflict Scales in a larger sample of bereaved AA family members of decedents with serious illnesses from a community setting, as well as in-patient or out-patient settings. Testing these instruments in a larger, more diverse sample will validate the current study's findings, and begin to build the evidence needed to develop interventions to improve communication and reduce conflict in EOL decision-making among AAs with serious illnesses and their families.

The next step would be to conduct a prospective, longitudinal mixed methods study. The aim of this study would be to explore how family members' relationships, decision-making, and communication with the healthcare teams impact care for patients who have been diagnosed with serious illnesses. To capture information along the care continuum, the investigator would collect information at three time points, including at initial diagnosis, when CFC is recommended, and following the patients' deaths. Quantitative measures including the Quality of Communication and Decisional Conflict Scales would be used at initial diagnosis and when CFC is recommended. After patients have died, the Decision Regret Scale will be used to assess family members' regrets regarding health care decisions. Qualitative interviews will be conducted with family members to assess their perceptions of the patient-family member-provider relationship, communication, and decision-making at initial diagnosis and when CFC is recommended.

After patients have died, qualitative interviews will assess family members' reactions to the health care decisions, including health care decisions that would be altered with hindsight. Given that most EOL studies are retrospective, gathering information prospectively could give important information regarding family member's

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communication and relationships with HCPs, as well as their decision outcomes as they are experiencing these phenomena.

The National Institutes of Health have called for interventions to enhance palliative care, treatment choices, decision-making, EOL care, patient-family member-provider communication; and reduce disparities in underserved populations [2]. To answer this call for interventions, future EOL studies should focus on intervention development that targets AAs with serious illnesses and their families. The goals of these interventions should focus on improving patient-family member-provider relationships and communication, as well as reducing decisional conflict. In contrast to much of existing literature, this study's findings indicate that cultural and religious values were not important to AA EOL decision-making, whereas quality of communication with HCPs played a critical role for AAs in their EOL care decisions. To this end, future intervention work should focus on improving communication between HCPs and AAs in EOL contexts.

Conclusion

AAs are disproportionately affected by high mortality rates for several serious illnesses, however prior research suggests that AAs underuse CFC, despite the benefits that CFC offers. The literature suggests that numerous factors are associated with AA EOL decision-making, including patient and family member characteristics and patient-family member-provider interaction. The findings of this study provide quantitative and qualitative evidence that indicates AA family members' EOL decision-making and decision outcomes are associated with the relationships and communication they have with HCPs. This study provides evidence that advances our understanding of decision-making, patient- and family member-centered communication, and the reasons why AAs chose to continue or discontinue LPT. Future research will build on this foundational work to inform intervention development, which should focus on improving

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communication and reducing decisional conflict among AAs with serious illness and their families.

Although evidence suggests that religion is a source of support for AAs, few investigators have explored how religious values support AAs in EOL decision-making[348]. In this study, family members did not mention that religious values contributed to their decision-making when they were asked, although the investigator did not report this finding in this dissertation. This information has extended the current state-of-the-science in EOL care and nursing research, and addressed EOL research priorities identified by national healthcare and research organizations.

Because this study examined decision-making from the perspective of the family member, valuable new knowledge has been generated, which ultimately will lead to interventions to support decision-making and enhance communication among AAs with serious illness, their families, and HCPs[75-78]. Lastly, the ODS and Quality of Communication Scales have not been applied in studies focused on ethnically diverse populations and seldom to patients at EOL. In fact, prior to this dissertation study, no study used the Quality of Communication and Decisional Conflict Scales jointly. This study has extended communication, ODS, and decision support science by contributing findings from an ethnically diverse sample of bereaved AA family members of patients who faced life-limiting illnesses at EOL.

Recruitment Letter

Date
Address

Dear:

I am sending you this letter to tell you about a study that is being conducted by the Indiana University School of Nursing. The purpose of the study is to understand our families' experiences with care provided for their loved ones who recently died. The study involves participating in a telephone interview to answer questions about your experiences with the care your loved one received.

The decision to participate in this program is entirely up to you. In this study, you will be asked to complete one telephone interview. The interview will take about 1 hour and 30 minutes and will be scheduled at a time that is convenient for you. You will be mailed one $25 gift card after completing the phone interview. **You will NOT be asked to take any medication or have any tests or examinations in this study.**

The researcher will call you in the next few days to see if you are interested. She will also answer any questions you may have about the study so you can decide if you want to join. If you have further questions or concerns, you may contact Esther Smith-Howell at (317) 288-5183. **If you prefer not to be contacted for this research study, simply call us at (317) 288-5183 to let us know.** Whether you decide to join this study or not is up to you, this study is completely voluntary.

Please know that this letter is being sent out and the study is being conducted by your loved one's [name] Physician's practice. No information about your loved one's health has been given to anyone outside of this practice.

Respectfully,

Gregory Gramelspacher, MD
Medical Director
Eskenazi Health Memorial Hospital Palliative Care Program

INDIANA UNIVERSITY STUDY INFORMATION SHEET FOR

End-of-Life Decision Making among African Americans with Serious Illness

You are invited to participate in a research study of end-of-life decision-making among African Americans with serious illness and their families. You are invited to participate in this study if you are the family member of a person who recently had serious illness. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by graduate student Esther Smith-Howell under the supervision of Dr. Susan Hickman, PhD at the Indiana University School of Nursing. It is funded by The National Institutes of Health.

STUDY PURPOSE

The overall purpose of this study is to learn how African Americans with serious illness and their families make decisions about end-of-life care. Many African Americans with serious illness could benefit from comfort-focused care such as hospice at the end-of-life, but most choose life-prolonging treatments instead. Information from this study will help to us identify how to help improve care for African Americans with serious illness and their families.

Participants will be asked to take part in a telephone interview, which could take approximately 35 to 50 minutes.

This study does not involve the use of any investigational drugs or devices, only questionnaires and surveys.

PROCEDURES FOR THE STUDY:

If you agree to be in the study, you will be asked do the following things:

You will be asked to participate in a 35 to 50-minute telephone interview. We will ask you to tell us who you are and answer questions about the kinds of decisions your loved one made in the last few weeks of life. You will also be asked a series of questions about you and your loved one's experiences in the last few weeks of life. This interview will be audio taped.

The interview will be scheduled for a time that is convenient for you. You will be given the option of taking a break during the interview if needed, to refuse to answer any questions that make you feel uncomfortable, and to withdraw from the study at any time without consequence. Your participation is completely voluntary.

CONFIDENTIALITY

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study

may be published and databases in which results may be stored. In order to protect you against the risk of a loss of privacy, interview data and questionnaires will be labeled with identification numbers, but not your name. All data forms will be kept in a locked file cabinet, available only to the researchers. All audio taped interviews will be downloaded into a secure computer, which is password-protected. Interviews will be transcribed and saved in an electronic format on a password-protected, secure computer. Identifying information such as names and places will be removed from the transcriptions. All digital data will be labeled with identification numbers, not your name, and will be kept in a password-protected computer. Digital data will be available only to the researchers. All data collected during the study will be destroyed after the conclusion of the study.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the researcher and her research associates, the Indiana University Institutional Review Board or its designees, the study sponsor, Indiana University School of Nursing, and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP), who may need to access your medical and/or research records.

PAYMENT

You will receive payment for taking part in this study. You will be mailed a $25 gift card after completing the phone interview.

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study, contact the researcher Dr. Susan Hickman at 317-274-0032 or Esther Smith-Howell at 317-288-5183.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (317) 278-3458.

VOLUNTARY NATURE OF STUDY

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Eskenazi Health (Wishard Memorial Hospital), Indiana University School of Nursing, or Eastern Star Church. If you decide to withdrawal from the study prior to completion, there is no risk to you or your healthcare.

Study Brochure

About the Researcher

I earned my Bachelor in Nursing Science from Indiana University School of Nursing in 2009. In April 2009, my Aunt Juanita died with lung cancer. Her quality of life might have been improved at the end of her life if communication between my family and her doctors and nurses had been better. I promised my Aunt I would earn a PhD and carry out research to improve end-of-life care for African Americans with advanced cancer.

Esther R. Smith-Howell

Contact for Questions
Esther Smith-Howell, BSN, RN
Phone: 317.288.5183

Susan Hickman, PhD
Phone: 317.274.0032

INDIANA UNIVERSITY
SCHOOL OF NURSING

End-of-Life Decision Making among African Americans with Advanced Cancer

Indiana University School of Nursing
Funded by
The National Institute of Nursing Research (1F31NR013613-01)

What is this study about?

The goal of this study is to learn how African Americans make decisions when they receive health care near the end of their life. To do this, we are asking family members to tell us what happened and how they felt when talking to doctors about their loved one's health care.

Who can join the study?

You can join this study if you:

- Have a telephone
- Are 21 years or older
- Are African American
- Helped care for a family member who recently passed away from advanced cancer

Why are you invited to join this study?

You are invited to join in this research study because you were listed as a family member of a person who recently passed away from advanced cancer.

What if you join the study?

If you join the study, you will:

- Complete a telephone interview, which could take up to **60 minutes**.

- Tell us who you are and answer questions about the kinds of decisions your loved one made in the last few weeks of life. The interview will include questions like:

    - "How did you first learn about your loved one's medical diagnosis?"

    - What helped you talk with the doctors on the health care team?"

How will we thank you for joining the study?

To show our thanks, you will receive a $25 gift card after completing the interview.

What if you start and don't want to finish?

You may choose not to take part or may leave the study at any time.

Appendix D

Data Collection Forms

Hello. May I please speak with Mr. / Ms. [last name]?

Hello, my name is Esther Smith-Howell with the Indiana University School of Nursing. Dr. Gramelspacher, your loved one [name]'s physician, has given me permission to speak with you regarding an end-of-life care study. Recently, we mailed you some information about this study. We're inviting the family members of patients who received care from the Eskenazi Health Palliative Care Program, who were involved in the patient's care and decision-making during the last month of life to be a part of the study.

So, let me confirm your role in the patient's care and I'll explain what the study is about to see if you're interested in participating.

As I mentioned earlier, we are only seeking family members who were somewhat or very involved in the patient's care. How involved would you say you were in [patient's name]'s care and decision-making during the last month of his/her life? Would you say that you were not involved at all, a little involved, somewhat involved, or very involved in your loved one's care?

↓   ↓

SOMEWHAT OR VERY INVOLVED   **NOT INVOLVED or A LITTLE INVOLVED**

↓   ↓

Great! Are you able to answer some questions about his/her and your experiences during care?

Thank you for that answer. Unfortunately, because you were not somewhat or very involved in the [patient's name]'s care, you're not eligible for the study.

But, I really appreciate you taking time to talk with me today. We will be happy to keep you in mind for any future studies that we might do. Goodbye

YES   **NO**

↓   ↓

NO

DON'T KNOW

Ok, thank you for that answer. Would you feel comfortable telling me if there is another family member who was involved in your loved one's care and/or decision-making who might be able to answer our questions concerning your loved one's experiences during care?

Who might that person be? Would you be willing to ask him/her if I could contact them about the study? I could call you back in a few days to get their contact information from you if they say that's OK.

Thank you for taking time to talk with me today. Goodbye.

Well, we do need to know that for this study.

I'd be happy to check with another family member whom you think was somewhat involved in your loved one's care and/or decision-making who might be able to answer questions concerning your loved one's experiences during care. Who might be a good person to call?

Thank you for taking time to talk with me today. Goodbye.

Great! Now, did you get the letter we sent you which talks about

YES   **NO**

May I have a few minutes of your time to tell you more about it?

I'm sorry! That must have gotten lost in the mail.

How about I go ahead and explain why I'm calling and then re-mail the letter to you?

NO

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Yes ↓

Well, this is a study were we are calling people on the phone to examine African American family members' opinions of the factors that influenced the end-of-life care decision-making for a relative with serious illness who has recently died. May I ask you a few questions to see if you're eligible for the study?

NO ↓

That's not a problem. I'm happy to call back in a few days. When would be a good time to call?

Alright. I look forward to talking with you again on [day, date, time].
Goodbye.

Eligibility Assessment Questions

According to your loved one [name]'s medical record, you're listed as next of kin. Are you a family member that was somewhat or very involved in your loved one's care and/or decision-making during the last month of his or her life?

- Yes – [Go to next question]

- No – Thank you for that answer. Unfortunately, although you are a family member, you weren't at least somewhat involved in the care and/or decision-making for your loved one, therefore you're not eligible for the study. But, I really appreciate you taking time to talk with me today. We will be happy to keep you in mind for any future studies that we might do. Goodbye.

Are you at least 21 years or older?

- Yes – [Go to next question]

- No – Thank you for that answer. Unfortunately, because you are not at least 21 years old, you're not eligible for the study. But, I really appreciate you taking time to talk with me today. We will be happy to keep you in mind for any future studies that we might do. Goodbye.

Are you African American?

- Yes – [Go to next question]

- No – Thank you for that answer. Unfortunately, because you're not African American, you're not eligible for the study. But, I really appreciate you taking time to talk with me today. We will be happy to keep you in mind for any future studies that we might do. Goodbye.

Are you a family member of decedent [name] by blood marriage, or other close affiliation?

- Yes – [Go to next question]

- No – Thank you for that answer. Unfortunately, because you're not a family member of the deceased patient by blood, marriage, or other close affiliation, you're not eligible for the study. But, I really appreciate you taking time to talk with me today. We will be happy to keep you in mind for any future studies that we might do. Goodbye.

Thank you for those answers. I'm happy to tell you that you're eligible for the study!

Explanation of Study

Now, let's talk more about what being in this study means. Included with the letter we sent was a form that explains what the study is about. Do you remember seeing that? If not, it's okay; I'll describe what you'll be asked to do.

- If you take part in the study, you will do one telephone interview, so we can learn more about African American perceptions of the factors that influenced end-of-life care decision-making for a relative with advanced caner who has recently died. All the information about you and your family member and whatever you tell us will be kept strictly confidential.

- The interview will take about an hour. We'll schedule the interview at a time that is convenient for you.

- You will be given a $25 gift card to thank you for your time. The gift card will be mailed to you after you finish the interview.

- Lastly, we understand that answer questions with a sensitive nature, such as a loved one's death could be difficult, and may make some people feel uncomfortable. You can refuse to answer any questions that make you uncomfortable, or that you feel are too personal. Your being in this study is completely voluntary, and not joining, or deciding not to participate in a second interview later is not a problem.

I know that was a lot of information. Do you have any questions?
If you think of any (more) questions at any point during the phone call, I will be happy to answer them.

Do you understand what I've told you and how the study works? Are you willing to participate?

YES ↓   ↓ **NO**

Great! We appreciate your willingness to help us. Again, the interview will take about one hour and 30 minutes. Are you still able to complete it now?

Ok, that's fine. It's helpful for our planning to know why people may not want to be in a study. Would you mind telling me why you are not interested?

Thank you for sharing that information. I won't take up anymore of your time today. Goodbye.

YES ↓   **NO** ↓

YES ↓   **NO** ↓

| Thank you, let's get started! |

| Not a problem, I'm happy to call you back at a time more convenient for you. When would be a better time to call you in the next few days?

I look forward to talking with you again on [day, date, and time]. Goodbye. |

Thank you again for agreeing to talk with me about your loved ones care and treatment in the last month of life. You and your loved one's background information is very important to our study, so I'd like you to start by asking you a few demographic questions about you and your loved one. If you cannot or don't feel comfortable answering certain questions about yourself of your loved one, it is okay. Your responses are completely voluntary and your refusal to answer will not have any negative impact on you at all.

A. Demographic Survey
   a. Ask questions from the Demographic Survey

I would like to better understand how treatment decisions were made, how you felt about your experiences with healthcare providers, and what helped you make it through this process. Now, I would like to ask you to share with me, from your perspective, what happened during your loved one's illness experience, leading up, and to include the last month of their life.

Next, I'd like to focus on the type of care your loved one received. In the last month of life, was the goal of your loved one's treatment focused on keeping him or her comfortable or more towards trying to cure to him or her of illness? For example, did the decedent receive comfort-focused care, such as hospice, or did they continue treatments to cure the illness?

B. Comfort-focused (CFC) or Life-prolonging Treatment (LPT)
   a. In the last month of life, was the goal of your loved one's treatment focused on keeping him or her comfortable without trying to cure his/her illness? (Comfort-focused care such as hospice)

   Or

   b. In the last month of life, was the goal of your loved one's treatment focused on treating the illness to cure your loved one?

Now, from your perspective, please reflect on the decisions made with or for your loved one to continue or discontinue life-prolonging treatments at end-of life, after talking with your loved one's doctor. Please show how strongly you agree or disagree with these statements by indicating a number from 1 (strongly agree) to 5 (strongly disagree) which best fits your views about the decision made regarding your loved one's care.

C. Decision Regret Scale
   a. Ask questions from the Decision Regret Scale
      i. Questions will be tailored to the type of treatment the participant's loved one received, either CFC or LPT

Now, from your perspective, considering the type of treatment your loved one received, please reflect on the decisions made with or for your loved one to continue or discontinue life-prolonging treatments at end-of-life, after taking with your loved one's doctor. Please answer yes, no, or unsure about the decisions made regarding your loved one's preferred treatment.

D. Decisional Conflict Scale
   a. Ask questions from the Decisional Conflict Scale
      i. Questions will be tailored to the type of treatment the participant's loved one received, either CFC or LPT

We are interested to learn about your religious views and how these views may have influenced may have influenced the decisions made with or for your loved one to continue or discontinue life-prolonging treatments at end-of life. Please show how strongly you agree or disagree with these statements by indicating a number from 4 (strongly agree) to 0 (strongly disagree) which best fits your views on religion in your daily life.

E. Beliefs and Values Scale
   a. Ask questions from the Beliefs and values Scale

We are interested to learn about how the quality of communication with the providers on the healthcare team influenced the care your loved one received. The following questions are about how well the healthcare team spoke with you about your loved one's care.

Please rate the healthcare team on each of the following questions using a scale from 0, "Poor" to 10, "Absolutely Perfect." The middle of the scale with the value of "5" indicates "Very Good." If you cannot rate the healthcare team on a questions because they did not do it, please say, "The team didn't do this." You may also say "I do not know."

F. Quality of Communication
   a. Ask questions from Quality of Communication Questionnaire

<u>**Demographic Survey**</u>

Participant and family member background information is very important to our study, so I'd like you to ask you a few demographic questions about you and your loved one. If you cannot or don't feel comfortable answering certain questions about yourself or your loved one, it is okay. Your responses are completely voluntary and your refusal to answer will have no negative impact on you whatsoever.

Let's start with a few questions about you…

1. How old are you? _____

2. Are you male or female?
> ❒ Male
> ❒ Female

3. Please stop me when I come the phrase that best describes your relationship to the family member? Where you his or her?
> ❒ Husband
> ❒ Wife
> ❒ Daughter or Step-daughter
> ❒ Son or Step-son
> ❒ Daughter-in-law
> ❒ Sister
> ❒ Brother
> ❒ Sister-in-law
> ❒ Brother-in-law
> ❒ Mother
> ❒ Father
> ❒ Niece
> ❒ Nephew
> ❒ Other Relative
> ❒ Friend

4. Please stop me when I come to the highest grade or year of school you finished. Is it?
> ❒ No school or kindergarten
> ❒ 1st grade to 5th grade (grade school)
> ❒ 6th grade to 8th grade (middle school)
> ❒ 9th grade to 11th grade (high school, without graduation)
> ❒ 12th grade/High school/Diploma/GED
> ❒ Vocational school (e.g., Technical/secretarial/business)
> ❒ Some college (no associates degree)
> ❒ Associates degree
> ❒ Graduated from college with 4 year degree
> ❒ Some graduate work
> ❒ Completed graduate degree

5. Please stop me when I come to your total combined yearly household income before taxes. Is it?
> ❒ 1. Less than $15,000
> ❒ 2. $15,000 - $30,000

❐ 3. $30,000 - $50,000
❐ 4. $50,000 - $75,000
❐ 5. $75,000 - $100,000
❐ 6. More than $100,000

6. What is your religious affiliation? _____

Now, I'd like to ask you a few questions about your loved one…

7. How old was your loved one when s/he passed away? _____

8. What was your loved one male or female?
    ❐ 1. Male
    ❐ 2. Female

9. Please stop me when I come to the highest grade or year of school your loved one finished. Is it?
    ❐ No school or kindergarten
    ❐ 1st grade to 5th grade (grade school)
    ❐ 6th grade to 8th grade (middle school)
    ❐ 9th grade to 11th grade (high school, without graduation)
    ❐ 12th grade/High school/Diploma/GED
    ❐ Vocational school (e.g., Technical/secretarial/business)
    ❐ Some college (no associates degree)
    ❐ Associates degree
    ❐ Graduated from college with 4 year degree
    ❐ Some graduate work
    ❐ Completed graduate degree

10. Please stop me when I come to your loved one's total combined yearly household income before taxes. Is it?
    ❐ 1. Less than $15,000
    ❐ 2. $15,000 - $30,000
    ❐ 3. $30,000 - $50,000
    ❐ 4. $50,000 - $75,000
    ❐ 5. $75,000 - $100,000
    ❐ 6. More than $100,000

11. What was your loved one's religious affiliation? _____

Decision Regret Scale (Continuation or Discontinuation of Life-prolonging Treatment)

From your perspective, please reflect on the decisions made with or for your loved one to continue or discontinue life-prolonging treatments at end-of life, after talking with your loved one's doctor. Please show how strongly you agree or disagree with these statements by indicating a number from 1 (strongly agree) to 5 (strongly disagree) which best fits your views about the decision made regarding your loved one's care.

Item	Response				
1. The decision to stop (or continue) treatment was the right decision.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
2. I regret the choice about treatment that was made for my loved one's end-of-life care.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
3. I would choose the same treatment plan again if I had to do it over.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
4. The choice of treatment at the end of my loved one's life did me a lot of harm.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
5. The choice to continue (or stop) treatment at the end of my loved one's life was a wise one.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree

Decisional Conflict Scale (Discontinuation of Life-prolonging Treatment)

You recently lost a family member to serious illness, taking into account your loved one's illness period:

A. Which type of treatment did your loved one received? Please check ☑ one.
    a. ☐ Life-prolonging treatment
    b. ☐ Comfort-focused care

B. Considering the option that was chosen for your loved one, please answer the following questions:

Item	Yes	Unsure	No
1. Did you and your loved one know which treatment options were available to you?	☐	☐	☐
2. Did you and your loved one know the benefits of each treatment option?	☐	☐	☐
3. Did you and your loved one know the risks and side effects of each treatment option?	☐	☐	☐
4. Were you and your loved one clear about which benefits mattered to you?	☐	☐	☐
5. Were you and your loved one clear about which risks and side effects mattered most to you?	☐	☐	☐
6. Did you and your loved one have enough support from others to make a choice?	☐	☐	☐
7. Were you and your loved one choosing without pressure from others?	☐	☐	☐
8. Did you and your loved one have enough advice to make a choice?	☐	☐	☐
9. Were you and your loved one clear about the best choice for your loved one's care?	☐	☐	☐
10. Did you and your loved one feel sure about what to choose?	☐	☐	☐

Beliefs and Values Scale

We are interested to learn about your religious views and how these views may have influenced may have influenced the decisions made with or for your loved one to continue or discontinue life-prolonging treatments at end-of life. Please show how strongly you agree or disagree with these statements by indicating a number from 4 (strongly agree) to 0 (strongly disagree) which best fits your views on religion in your daily life.

Item	Response				
1. I am a spiritual person.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
2. I believe I have a spirit or soul that can survive my death.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
3. I believe in a personal God.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
4. I believe meditation has value.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
5. I believe God is an all-pervading presence.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
6. I believe what happens after I die is determined by how I have lived my life.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
7. I believe there are forces for evil in the Universe.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree

Item	Response				
8. Although I cannot always understand, I believe everything happens for a reason.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
9. I believe human physical contact can be a spiritual experience.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
10. I feel most at one with the world when surrounded by nature.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
11. I believe in life after death.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
12. I am a religious person.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
13. Religious ceremonies are important to me.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
14. I believe life is planned out for me.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
15. I believe God is a life force.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree

Item	Response				
16. At least once in my life, I have had an intense spiritual experience.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
17. I believe that there is a heaven.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
18. I believe the human spirit is immortal.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
19. I believe prayer has value.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree
20. I believe there is a God.	4 Strongly Agree	3 Agree	2 Neither Agree Nor Disagree	1 Disagree	0 Strongly Disagree

Quality of Communication

We are interested to learn about how the quality of communication with the providers on the healthcare team influenced the care your loved one received. The following questions are about how well the healthcare team spoke with you about your loved one's care.

Please rate the healthcare team on each of the following questions using a scale from 0, "Poor" to 10, "Absolutely Perfect." The middle of the scale with the value of "5" indicates "Very Good." If you cannot rate the healthcare team on a questions because they did not do it, please say, "The team didn't do this." You may also say "I do not know."

How good was the healthcare team at:

Item	Poor				Very Good				Absolutely Perfect			The Team Did Not Do This	I Do Not Know
Used words you understand…	0	1	2	3	4	5	6	7	8	9	10	❐	❐
Looked you in the eye…	0	1	2	3	4	5	6	7	8	9	10	❐	❐
Answered all questions about your loved one's illness…	0	1	2	3	4	5	6	7	8	9	10	❐	❐
Listened to what you had to say…	0	1	2	3	4	5	6	7	8	9	10	❐	❐
Cared about you as a person…	0	1	2	3	4	5	6	7	8	9	10	❐	❐

Item	Poor				Very Good				Absolutely Perfect			The Team Did Not Do This	I Do Not Know
Gave you his/her full attention…	0	1	2	3	4	5	6	7	8	9	10	❒	❒
Talked about your feelings about your loved one getting sicker…	0	1	2	3	4	5	6	7	8	9	10	❒	❒
Talked about details as your loved one got sicker…	0	1	2	3	4	5	6	7	8	9	10	❒	❒
Talked about how long your loved one had to live…	0	1	2	3	4	5	6	7	8	9	10	❒	❒
Talked about what dying might be like…	0	1	2	3	4	5	6	7	8	9	10	❒	❒
Involved you in treatment discussions about your loved one's care…	0	1	2	3	4	5	6	7	8	9	10	❒	❒

Item	Poor				Very Good				Absolutely Perfect			The Team Did Not Do This	I Do Not Know
Asked you about important things in life…	0	1	2	3	4	5	6	7	8	9	10	❐	❐
Asked you about your loved one's spiritual, religious beliefs…	0	1	2	3	4	5	6	7	8	9	10	❐	❐

Script for Second Portion of Interview

Now, let me give you tell you a little information about the second portion of the interview. This portion of the interview will take about one hour to complete and will consist of open-ended questions about your loved ones care and treatment in the last month of life. The information you provide will help us to better understand how treatment decisions were made, how you felt about your experiences with healthcare providers, and what helped you make it through this process.

Lastly, we understand that answering questions with a sensitive nature, such as a loved one's death could be difficult, and may make some people feel uncomfortable. You can refuse to answer any questions that make you uncomfortable, or that you feel are too personal. Your being in this study is completely voluntary; deciding not to participate in the second portion of the interview is not a problem.

I know that was a lot of information. Do you have any questions?
If you think of any (more) questions, I will be happy to answer them.

Thank you again for your time, Mr. / Ms. [name]. We greatly appreciate your willingness to continue with the second portion of the study!

Thank you again for agreeing to talk with me about your loved ones care and treatment in the last month of life. I would like to better understand how treatment decisions were made, how you felt about your experiences with healthcare providers, and what helped you make it through this process.

I know we spoke about the last month of your loved ones life during our first portion of the telephone conversation, now I would now like to ask you a few more specific questions.

1. How did you first learn about your loved one's medical diagnosis?
    a. What did you know about this condition at the time he/she was diagnosed?
    b. Did this knowledge change over time?

2. Tell me about the first discussion that you and/or your loved one had with the healthcare team regarding the treatment options that were available.
    a. What were your thoughts about the outcomes of these treatment options?
    b. Did you and your loved one have similar or different thoughts about the treatment outcomes as the healthcare team?
        i. How were they similar or different?

3. During the last month of your loved one's life, what treatment options were discussed with the healthcare team?
    a. Did any particular treatment type come to mind as better than another during this later stage?
    b. How often were your discussions with the healthcare team?
    c. How did these discussions influence your and your loved one's treatment decisions?

4. What were your thoughts regarding end-of-life care as a treatment option?
   a. You chose (either comfort-focused care or life-prolonging treatment), why?

5. During the last week of your loved one's life, were you prepared for the events that occurred, or did things happen as a surprise to you?

6. What were sources of comfort and guidance during this time for you and your loved one?

7. How did religious values influence your decision towards or against life-prolonging treatment or comfort-focused care?

8. Please describe what cultural values, if any, that were important to you and your loved one as you made decisions about your loved one's healthcare. By cultural values, I mean things that are important to you as an African American.

9. How would you describe your relationship with the healthcare team?
   a. How did trust play a role in this relationship?
   b. Describe an instance where you felt you could not trust the healthcare team.

10. What was helpful to your communication with the healthcare team?
    a. Describe situations where the communication could have been better.

11. If you could do it all over, what, if anything, would you do differently?

12. Is there anything else you would like to share with me about your loved ones care in the final months of life?

Appendix E

<u>Normality Tests of Study Measures</u>

Variable	Skewness	SE	Kurtosis	SE	Shapiro-Wilk	Conclusion
Religious Values	-1.00	0.34	1.72	0.67	p=.008	Not normal
Square-Root Religious Values	0.02	0.34	-0.29	0.67	p=.698	Normal
Log-Religious Values	-0.99	0.34	0.76	0.67	p=.004	Not normal
Inverse-Religious Values	3.37	0.34	12.11	0.67	p=.000	Not normal
Quality of General Communication	-1.20	0.34	0.62	0.67	p=.000	Not normal
Square Root-Quality of General Communication	0.75	0.34	-.050	0.67	p=.000	Not normal
Log-Quality of General Communication	0.33	0.34	-1.13	0.67	p=.003	Not normal
Inverse-Quality of General Communication	0.34	0.34	-1.37	0.67	p=.000	Not normal
Quality of End-of-life Communication	-0.36	0.34	-0.72	0.67	p=.072	Normal
Decision Regret	0.88	0.34	0.84	0.67	p=.005	Not normal
Square Root-Decision Regret	-0.37	0.34	-0.35	0.67	p=.049	Near normal
Log-Decision Regret	-1.16	0.34	0.56	0.67	p=.000	Not normal
Inverse-Decision Regret	2.28	0.34	3.53	0.67	p=.000	Not normal
Decisional Conflict	1.00	0.34	0.02	0.67	p=.000	Not normal
Square Root-Decisional Conflict	0.02	0.34	-1.12	0.67	p=.000	Not normal

Variable	Skewness	SE	Kurtosis	SE	Shapiro-Wilk	Conclusion
Log-Decisional Conflict	-0.57	0.34	-1.19	0.67	p=.000	Not normal
Inverse-Decisional Conflict	1.07	0.34	-0.85	0.67	p=.000	Not normal

Appendix F

Descriptive Statistics of Beliefs and Values Scale Items and Scores

Item	Total Sample (n = 49)						
	Response						
	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree		
	n (%)	*n (%)*	*n (%)*	*n (%)*	*n (%)*	Mean	SD
I am a spiritual person.	29 (59.2)	18 (36.7)	0 (0.0)	2 (4.1)	0 (0.0)	3.51	0.71
I believe I have a spirit or soul that can survive my death.	26 (53.1)	16 (32.7)	1 (2.0)	4 (8.2)	2 (4.1)	3.22	1.10
I believe in a personal God.	29 (59.2)	18 (36.7)	0 (0.0)	2 (4.1)	0 (0.0)	3.51	0.71
I believe meditation has value.	17 (34.1)	25 (51.0)	5 (10.2)	2 (4.1)	0 (0.0)	3.16	0.77
I believe God is an all-pervading presence.	27 (55.1)	18 (36.7)	1 (2.0)	3 (6.1)	0 (0.0)	3.41	0.81
I believe what happens after I die is determined by how I have lived my life.	19 (38.8)	17 (34.7)	4 (8.2)	9 (18.4)	0 (0.0)	2.94	1.11
I believe there are forces for evil in the universe.	21 (42.9)	25 (51.0)	1 (2.0)	2 (4.1)	20 (0.0)	3.33	0.72
Although I cannot always understand, I believe everything happens for a reason.	27 (55.1)	18 (36.7)	2 (4.1)	2 (4.1)	0 (0.0)	3.43	0.76

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree		
	n (%)	*n (%)*	*n (%)*	*n (%)*	*n (%)*	Mean	SD
I believe human physical contact can be a spiritual experience.	17 (34.7)	25 (51.0)	4 (8.2)	2 (4.1)	1 (2.0)	3.12	0.88
I feel most at one with the world when surrounded by nature.	9 (18.4)	21 (42.9)	9 (18.4)	10 (20.4)	0 (0.0)	2.59	1.02
I believe in life after death.	21 (42.9)	17 (34.7)	5 (10.2)	5 (10.2)	1 (2.0)	3.06	1.07
I am a religious person.	20 (40.8)	22 (44.9)	4 (8.2)	3 (6.1)	0 (0.0)	3.20	0.84
Religious ceremonies are important to me.	12 (24.5)	26 (53.1)	4 (8.2)	7 (14.3)	0 (0.0)	2.88	0.95
I believe life is planned out for me.	12 (24.5)	25 (51.0)	3 (6.1)	8 (16.3)	1 (2.0)	2.80	1.06
I believe God is a life force.	25 (51.0)	21 (42.9)	1 (2.0)	2 (4.1)	0 (0.0)	3.41	1.00
At least once in my life, I have had an intense spiritual experience.	22 (44.9)	18 (36.7)	3 (6.1)	6 (12.2)	0 (0.0)	3.14	1.00
I believe that there is a heaven.	29 (59.2)	16 (32.7)	2 (4.1)	2 (4.1)	0 (0.0)	3.47	0.77
I believe the human spirit is immortal.	18 (36.7)	21 (42.9)	4 (10.2)	1 (2.0)	1 (2.0)	3.02	1.03
I believe prayer has value.	35 (71.4)	14 (28.6)	0 (0.0)	0 (0.0)	0 (0.0)	3.71	0.46

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree		
	_n (%)_	_n (%)_	_n (%)_	_n (%)_	_n (%)_	Mean	SD
I believe there is a God.	37 (75.5)	11 (22.4)	1 (2.0)	0 (0.0)	0 (0.0)	3.71	0.58
Total Religious Beliefs and Values Scale Mean (SD)						64.6	(10.4)
Min. and Max. Scores						28	79

Note. *The scale ranges from 0-80.*

Appendix G

Descriptive Statistics of the Quality of Communication Scores

Total Sample (n = 49)		
Item		
How good was the healthcare team at:	Mean	(SD)
Using words you understood?	7.82	(2.70)
Looking you in the eye?	8.55	(2.00)
Answering all questions about your loved one's illness?	8.16	(2.20)
Listening to what you had to say?	8.39	(2.22)
Caring about you as a person?	7.63	(2.73)
Giving you their full attention?	7.86	(2.68)
Talking about your feelings as your loved one got sicker?	6.84	(3.54)
Talking about details as your loved one got sicker?	7.55	(2.86)
Talking about how long your loved one had to live?	6.35	(3.88)
Talking about what dying might be like?	3.51	(4.30)
Involving you in treatment discussions about loved one's care?	7.80	(3.12)
Asking you about important things in life?	5.10	(4.06)
Asking about your loved one's spiritual and religious beliefs?	4.82	(4.25)
Total Quality of General Communication Scale Mean (SD)	8.07	(2.13)
Total Quality of End-of-life Communication Scale Mean (SD)	5.99	(2.78)
General Communication Min. and Max. Scores	1.83	10
End-of-life Communication Min. and Max. Scores	0.14	10

Note. Possible range of score zero (poor) to 10 (absolutely perfect).

Appendix H

Frequencies of End-of-life Care Decision

Total Sample (n = 49)		
Decision	*n*	*(%)*
Comfort-Focused Care	31	(63.3)
Life-Prolonging Treatment	18	(36.7)

Appendix I

<u>Descriptive Statistics of Decision Regret Items and Scores</u>

Total Sample (n = 49)							
Item	Response						
	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree		
	<u>n (%)</u>	<u>n (%)</u>	<u>n (%)</u>	<u>n (%)</u>	<u>n (%)</u>	<u>Mean</u>	<u>SD</u>
The decision to (stop or continue) life-prolonging treatment was the right decision.	27 (55.1)	17 (34.7)	3 (6.1)	2 (4.1)	0 (0.0)	1.59	0.79
I regret the choice about treatment that was made for my loved one's end-of-life care.	2 (4.1)	2 (4.1)	3 (6.1)	23 (46.9)	19 (38.8)	1.88	0.99
I would choose the same treatment plan again if I had it to do over.	14 (28.6)	24 (49.0)	4 (8.2)	5 (10.2)	2 (4.1)	2.12	1.07
The choice of treatment at the end of my loved one's life did me a lot of harm.	1 (2.0)	6 (12.2)	3 (6.1)	20 (40.8)	19 (38.8)	1.98	1.07
The choice to continue (or stop) treatment at the end of my loved one's life was a wise one.	22 (44.9)	18 (36.7)	4 (8.2)	3 (6.1)	2 (4.1)	1.88	1.07
Total Regret Scale Mean (SD)						22.2	(17.8)
Min. and Max. Scores						0	80

Note: Possible range of scores 0 (no decision regret) to 100 (high decision regret).

Appendix J

Descriptive Statistics of Decisional Conflict Scale Items and Scores

	Total Sample (n = 49)				
Item		Response			
	Yes	No	Unsure		
	n (%)	n (%)	n (%)	Mean	SD
Did you and your loved one know which treatment options were available to you?	31 (63.3)	9 (18.4)	9 (18.4)	1.10	1.58
Did you and your loved one know the benefits of each treatment option?	33 (67.3)	9 (18.4)	7 (14.3)	1.02	1.59
Did you and your loved one know the risks and side effects of each treatment option?	33 (67.3)	12 (24.5)	4 (8.2)	1.14	1.73
Were you and your loved one clear about which benefits mattered most to you?	33 (67.3)	11 (22.4)	5 (10.2)	1.10	1.67
Were you and your loved one clear about which risks and side effects mattered most to you?	27 (55.1)	12 (24.5)	10 (20.4)	1.39	1.69
Did you and your loved one have enough support from others to make a choice?	40 (81.6)	6 (12.2)	3 (6.1)	0.61	1.37
Were you and your loved one choosing without pressure from others?	36 (73.5)	11 (22.4)	2 (4.1)	0.98	1.69
Did you and your loved one have enough advice to make a choice?	39 (79.6)	6 (12.2)	4 (8.2)	0.65	1.38
Were you and your loved one clear about the best choice for your loved one's care?	33 (67.3)	9 (14.3)	7 (14.3)	1.02	1.59

	Total Sample (n = 49)				
Item		Response			
	Yes _n (%)_	No _n (%)_	Unsure _n (%)_	Mean	SD
Did you and your loved one feel sure about what to choose?	31 (63.3)	10 (20.4)	8 (16.3)	1.14	1.63
Total Decisional Conflict Scale Mean (SD)				25.41	(26.20)
Min. and Max. Scores				0	90

Note. Possible range of scores zero (no decisional conflict) to 100 (extremely high decisional conflict).

Codes, Sub-Codes, and Sub-Code Definitions

CODE (definition)	SUB-CODES	SUB-CODE DEFINITION
1. **Comfort and Managing** Coping mechanisms which helped decedents and family members manage the end-of-life care process. Coping mechanisms included using faith, family, decedents' dispositions, decedents' religious status, social support, a visage of strength, and family members working on the decedent's behalf.	Decedent's Disposition	The decedent's disposition about dying often helped family members to be at peace with the process. If the decedent was at peace, the family member was also at peace.
	Decedent's Religious Status	Family members felt at peace knowing the decedent had a relationship with God and were "saved".
	Faith as Comfort	Using aspects of faith as comfort.
	Fight	A fighting spirit helped get the family member through the end-of-life care process.
	Professional Support	Professional support in terms of health care, nursing care, procedures, and supplies
	Social Support	Support from family members, church members, and medical staff.
	Taking Care of Decedent	Family member received comfort and peace from working for decedent's happiness and comfort.
	Visage of Strength	When family members showed strength on their faces, hid tears from decedents, and generally portrayed courage and happiness during the dying process.
	Keeping Busy	Working or staying busy as a way to cope with the stress of the decedent's illness.
2. **Cultural Values** How cultural values influenced care decision-making. Cultural values include aspects of African	Faith in Decision-making	Faith, as a cultural value, influenced decision-making. Faith is taught and lived.
	Family Values	Family members are involved in the care of the decedent. Family member involvement

CODE (definition)	SUB-CODES	SUB-CODE DEFINITION
American culture, including keeping traditions, teachings, and maintaining privacy/secrecy. Explanations of why culture did not play a role in decision-making are also given.		includes members being delegated roles in order to make the end-of-life care process unfold as smoothly as possible. Involvement also served as a way to keep healthcare team accountable for the standard of care decedent received, Family members felt that when they were preset, the decedent received better care. Family involvement also included family unity, family caring for family, and caring for decedent in the family home.
	Secrecy	Decedent not willing to tell family about diagnosis or the family not willing to tell decedent about diagnosis or end-of-life care.
	Traditions	The traditions and teaching that have been passed down from one generation to the next.
	Decedent's comfort and Quality of Life	The desire for the decedent to be as comfortable as possible played a role in decision-making.
	Preserving decedent's pride	Ensuring that the decedent experiences the end-of-life care process with dignity.
	No role	When cultural values played no role in decision-making regarding decedent's care.
3. Religious Values Thoughts about religion and how religious values influence care decision-making. Religious values include thoughts related to God's will, God's healing, and if no	God's Healing	Decedents and family members believed and hoped that God' power to heal would help the decedent recover from illness and return to normal life. This belief was often based on previous experiences, teachings, and blind faith.

CODE (definition)	SUB-CODES	SUB-CODE DEFINITION
religious values contributed to decision-making.	God's Help	Family members asking for God's help in decision-making and care of the decedent.
	God's Will	Decedents and family member believed God's will, predetermination, and plan would allow events to unfold. Individuals believed that God's will would guide them in decision-making.
	Prayer	The role prayer played in decision-making, coping, and surviving the end-of-life process.
	No role	When religious values played no role in decision-making.
	Disillusionment with God	Feeling let down by God, despite doing what "supposed to do," death occurred anyway.
4. **Knowledge** (Aim 3) Knowledge acquisition (inquiries and Previous exposure) and knowledge giving is also important. How family members found out about decedent's condition.	Knowledge Acquisition	How the decedent and family member obtained knowledge about diagnosis, treatment options, and end-of-life care. Family members and decedents may have gained knowledge from the healthcare team, by suggestions from friends or family, by previous exposure, by asking the healthcare team, or via avenues beyond the healthcare team.
	Lack of knowledge	Lack of knowledge about diagnosis, treatment options, treatment outcomes.
	Desire for Knowledge	When reflecting over the entire end-of-life experience, family members desire more knowledge to make different decisions.
5. **Understanding** (Aim 3) Understanding (and lack of understanding) about diagnosis,	Diagnosis	Decedent and family member's understanding about the condition which the decedent was diagnosed.

CODE (definition)	SUB-CODES	SUB-CODE DEFINITION
treatment outcomes, and end-of-life care options. Application of knowledge.	Treatment options	Understanding of treatment options.
	Treatment outcomes	Understanding of treatment outcomes
	Changes in condition	Understanding the physical changes decedent's body undergoes as death approaches, and becoming aware things are not going well for the decedent.
	Prepared for death	Highlights factors that helped decedents and families be prepared for death.
	Unprepared for death	Highlights factors that caused decedents and family members to be unprepared for death.
	Lack of Understanding	Lack of understanding regarding decedent's diagnosis, treatment options, and treatment outcomes.
6. Relationship with Healthcare Team (Aim 3)	No relationship	Family members felt there was no relationship with the healthcare team.
How relationship with the healthcare team influenced decision-making. Aspects of positive and negative relationships are highlighted.	Being shown care	Family members reported relationships with healthcare providers (HCP) were positive when HCPs showed that they cared. Family members described HCPs' exhibition of care in several ways, including when HCPs showed respect, empathy, concern, kindness, were honest, and took genuine interest in helping the decedent and family member.
	Being shown a lack of concern	Family members' reports of negative relationships with HCP were frequently connected to perceptions that HCPs showed a lack of concern for decedents' care. Family members felt disconnected from the healthcare team when they

CODE (definition)	SUB-CODES	SUB-CODE DEFINITION
		perceived HCPs to provide disingenuous or feigned care.
	Distrusting	Highlights elements of distrust in the relationship, including: uncivil treatment by HCPs, HCPs' lying, belittling, and condescending behaviors and communication. Distrust is also perceived by the lack of value HCPs place on the decedents' lives as exhibited by poor quality of care given or limited efforts given to save the decedents' lives.
	Feeling HCP are available and attentive	
	Felt HCP had expertise	Felt HCP had expertise and was competent to care for decedent.
	FM Kept Informed	HCPs kept family members informed about decedent's condition and care.
	Valued life	HCPs valued decedent's life and worked to provide the best care possible.
	Inconsiderate care	Providing care that was inconsiderate to the decedent and family member. This may have included cancelling appointments, rushing decedents to discharge.
	Life is undervalued	Distrust is perceived by the lack of value the HCT places on the decedent's life as exhibited by the poor quality of care given or limited efforts given to save the decedent's life.
	Perceived substandard or incompetent care	
	Took Cover	HCPs took over decedent's care and decision-making.

CODE (definition)	SUB-CODES	SUB-CODE DEFINITION
	Uncivil treatment	Distrust is perceived by uncivil treatment by healthcare team, healthcare team lying, belittling, and condescending behaviors and communication
	Trusting	Factors that influenced the trust decedents and family members had in the healthcare team. These factors included, but were not limited to healthcare team's expertise and the value they placed in the decedent's life as exhibited by the effort they gave to saving the life.
	Lack of Instrumental Support	Lack of support with logistics and navigating healthcare.
7. **Quality of Communication (Aim 3)** How communication with the healthcare team influenced decision-making. Aspects of helpful and poor communication are highlighted.	Untailored communication	Communication that does not take the family member's communication preferences (i.e., speaking with a team versus speaking with one HCP) into consideration.
	No team effort	Family member and decedent receive care from one HCP rather than a team of HCPs.
	Family member exclusion	When the FM is excluded from participating in decedent's care. The family member's opinions regarding care are not taken into consideration.
	Family member-HCP conflict	Conflict that arises between family members and HCPs regarding the decedent's treatment.
	Inadequate or limited information	Decedents and family members being provided with limited information. When given limited or inadequate information family members express desires for additional information to make decisions and future plans.

CODE (definition)	SUB-CODES	SUB-CODE DEFINITION
	Paternalistic	HCPs make decisions about decedent's care without involving the family member. The HCP essentially takes the autonomy of the decedent and family member and makes decisions on their half.
	Inconsiderate Communication	Communication that did not take into consideration the decedent's or family member's feelings and desires regarding care.
	Being informed	Family members perceived communication that gave them information regarding the decedent's care as helpful.
	Continuity of communication	Family member preference to speak with the same person on the HCT rather than multiple providers.
	Family member inclusion	Family members desired to be included in decision-making and discussions regarding the decedent's care.
	Interdisciplinarity-Connectedness	Family member desired to work with an interdisciplinary healthcare team, which included individual providers on the team communicating with one another.
	Openness, honesty	Family member desired open and honest communication with HCPs.
	Shared expectations	When HCT and family members have the same expectations for the decedent's care and outcomes.
	Availability	Being available to speak with family members regarding decedents' care.
	Showing care	(see Relationships with Healthcare Team)
	Understandability	Family members desired for HCPs to speak using layman's terms. Simple language

CODE (definition)	SUB-CODES	SUB-CODE DEFINITION
		increased family members' understanding of communication regarding decedents' care.
8. Decisions to Continue Life-prolonging Treatment (LPT) (Aim 4) Family members' thoughts about life-prolonging treatment and why they chose to use it or not.	Lack of understanding	Lack of understanding regarding the severity of decedents' illnesses.
	No other option given	Family member felt there was no other medical option beyond continuing to use LPTs.
	Believe Will Benefit	Belief the patient will benefit from continued LPT. Patient receives care as a matter of routine care.
	Patient Preferences for LPT	Patient preferences to continue LPT drive care.
	Unwilling to give up	When decedents and/or family members are unwilling to give up LPT.
9. Decisions to Discontinue LPT (Aim 4) Family members' thoughts about comfort-focused care and why they chose to use it or not.	Advice from Others	Family member took advice from others (i.e., HCPs) regarding decedent's care.
	Avoid Placement	Reason to discontinue is to receive services in the home rather than be placed in a facility.
	Conflict w/HCPs	Family member chose hospice due to conflict with treating HCPs.
	HCP Decided	HCP decides the treatment decedent receives, rather than family member, or shared decision with family member.
	Just Happened (not a decision)	End-of-life (EOL) occurred too quickly, and no decision could be made
	Need Help - Overwhelmed	Decedent's physical care needs were too great for the family member to complete at home, so family members received help in caring for decedents. Help from hospice

CODE (definition)	SUB-CODES	SUB-CODE DEFINITION
		and palliative care served as a support for families caring for decedents.
	Patient preferences	Patient wanted to discontinue LPT.
	Prevent suffering	Decedents and family members chose hospice to prevent the decedent from suffering.
10. Reflections (Aim 3)	Acceptance	Comfort with the decisions made, would not have changed the decision.
	Regrets	Would have made different decisions and wished for a different outcome. May also include anger with outcome and wishing for a better outcome.
11. Good Quotes		Exemplar quotes
12. Case Summary Summary of each family member's end-of-life care experience.		Range of experiences, both positive and negative.
13. Quotes to Discuss		Quotes that do not fit into a category, but seem to have significance.

Appendix L

SPSS Syntax for Aims 1 and 2

*Aim 1. Describe characteristics of African American decedents and family members, as well as, religious values, quality of communication,
end-of-life treatment decision, and decision outcomes of bereaved African American family members.

*Frequencies - Family Member Age, Income, Education, and Religious Affiliation.
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    education_2Group ReligiousAffiliation
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*Frequencies - Decedent Age, Gender, Income, Education, and Religious Affiliation.
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education2_2Group ReligiousAffiliation2
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  /ORDER=ANALYSIS.

*Frequencies - Family Member Religious Beliefs & Values.
FREQUENCIES VARIABLES=spiritual_person soul_survives_death
believe_in_personal_god
    meditation_has_value god_is_all_prevading life_determines_afterlife evil_in_universe
    happens_for_a_reason human_contact_spiritual one_with_nature believe_in_afterlife
    am_a_religious_person religious_ceremony_important life_planned_out
god_is_life_force
    intense_spiritual_exp there_is_a_heaven human_spirit_immortal prayer_has_value
there_is_a_god
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  /ORDER=ANALYSIS.

*Frequencies - Family Member Quality of Communication.
FREQUENCIES VARIABLES=WORDSr EYEr QUESr LISTENr CAREr ATTENTr FEELr
DETAILr LONGr DIELIKEr PATDMr
    LIFEr ASKSPIRr
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  /ORDER=ANALYSIS.

*Frequencies - Family Member EOL Decision.
FREQUENCIES VARIABLES=EOL_Decision
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  /ORDER=ANALYSIS.

*Frequencies - Family Member Decisional Conflict.
FREQUENCIES VARIABLES=conflict_1 conflict_2 conflict_3 conflict_4 confict_5
confict_6 confict_7
    conflict_8 conflict_9 conflict_10
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*Frequencies - Family Member Decisional Conflict Tertile.
FREQUENCIES VARIABLES=Decisional_Conflict_Tertile
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*Frequencies - Family Member Decision Regret.
FREQUENCIES VARIABLES=regret_1 regret2r regret_3 regret4r regret_5
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*Frequencies - Family Member Religious Beliefs, Decisional Conflict, Decision Regret,
Quality of Communication Total Scores.
FREQUENCIES VARIABLES=Total_Religious_Beliefs_Values_Score QOCgen QOCeol
Total_Regret_Score Total_Conflict_Score
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_____.
*Aim 2. Examine relationships among decedent and family member characteristics,
religious values, quality of communication, end-of-life treatment decision, and decision
outcomes.

*Research Question 2a. What are the relationships between decedents' characteristics
and:
1) quality of communication; 2) end-of-life treatment decision; and 3) decision
outcomes?

*Quality of General Communication.
*Decedent Characteristics.
*Decedent Age.
*See 2c.

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*Religious Values.
*See 2c.
*_____.
*Quality of EOL Communication.
*Decedent Characteristics.
*Age.
*See 2c.

*Gender.
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*Religious Values.
*See 2c.
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*EOL Treatment Decision.
*Age.
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*Decision Regret.
*Age.
*See 2c.

*Gender.
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*Religious Values.
*See 2c.
*_____.
*Decisional Conflict.
*Age.
*See 2c.

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*Religious Values.
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*Research Question 2b. What are the relationships between bereaved family members'
characteristics and: 1) quality of communication;
 2) end-of-life treatment decision; and 3) decision outcomes?

*Family Member Characteristics.
*Quality of General Communication.
*Age.
*See 2c.

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*Religious Affiliation.
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*Religious Values.
*See 2c.
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*Quality of EOL Communication.
*Family Member Characteristics.
*Age.
*See 2c.

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*Religious Values.
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*Age.
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*Decision Regret.
*Age.
*See 2c.

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*Religious Values.
*See 2c.
*_____.
*Decisional Conflict.
*Age.
*See 2c.

*Gender.
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*Income.
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*Religious Affiliation.
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*Religious Values.
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*_____

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*Research question 2c.  What are the relationships among family members' quality of
communication and decision outcomes?.

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treatment decision?.

*Decision Regret by EOL treatment decision.
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*Decisional Confict by EOL treatment decision.
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*Research question 2e. Are there differences in quality of communication by end-of-life treatment decision?

*Quality of General Communication.
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*Quality of EOL Communication.
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*_____

_____.
*Research question 2f. What antecedents and mediator in the conceptual model predict end-of-life treatment decision?.

*EOL Decision.
*Decedent Characteristics.
*Age.
LOGISTIC REGRESSION VARIABLES EOL_Decision
  /METHOD=ENTER age2
  /PRINT=CI(95)
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Gender.
LOGISTIC REGRESSION VARIABLES EOL_Decision
  /METHOD=ENTER decedent_gender2
  /CONTRAST (decedent_gender2)=Indicator(1)
  /PRINT=CI(95)
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Income.
LOGISTIC REGRESSION VARIABLES EOL_Decision
  /METHOD=ENTER income2_Group2
  /CONTRAST (income2_Group2)=Indicator(1)
  /PRINT=CI(95)
  /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

*Education.
LOGISTIC REGRESSION VARIABLES EOL_Decision
  /METHOD=ENTER education2_2Group
  /CONTRAST (education2_2Group)=Indicator(1)
  /PRINT=CI(95)
  /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).
*_____.
*Family Member Characteristics.

```
*Age.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER age
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).


*Gender.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER gender
 /CONTRAST (gender)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).


*Income.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER income_2Groups
 /CONTRAST (income_2Groups)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).


*Education.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER education_2Group
 /CONTRAST (education_2Group)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).


*Religious Values.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER Reflected_Sqrt_Religious_Values
 /PRINT=GOODFIT CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).
*_____.
*Quality of General Communicaiton.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER Dichotomized_QOCgen
 /CONTRAST (Dichotomized_QOCgen)=Indicator(1)
 /CLASSPLOT
 /PRINT=GOODFIT CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).


*Age.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER age
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).


*Gender.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER gender
 /CONTRAST (gender)=Indicator(1)
```

```
/PRINT=CI(95)
/CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

* Income.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER income_2Groups
 /CONTRAST (income_2Groups)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

* Education.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER education_2Group
 /CONTRAST (education_2Group)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

*Religious Values.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER Reflected_Sqrt_Religious_Values
 /PRINT=GOODFIT CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*EOL Decision, Quality of General Communication, and Education.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER Dichotomized_QOCgen education_2Group
/CONTRAST (Dichotomized_QOCgen)=Indicator(1)
 /CONTRAST (education_2Group)=Indicator(1)
 /CLASSPLOT
 /PRINT=GOODFIT CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).
*_____.
*Quality of EOL Communication.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER QOCeol
 /SAVE=PGROUP
 /CLASSPLOT
 /PRINT=GOODFIT CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Age.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER age
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

*Gender.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER gender
 /CONTRAST (gender)=Indicator(1)
 /PRINT=CI(95)
```

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  /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

* Income.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER income_2Groups
 /CONTRAST (income_2Groups)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

* Education.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER education_2Group
 /CONTRAST (education_2Group)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

*Religious Values.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER Reflected_Sqrt_Religious_Values
 /PRINT=GOODFIT CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*EOL Decision, Quality of EOL Communication, and Education.
LOGISTIC REGRESSION VARIABLES EOL_Decision
 /METHOD=ENTER QOCeol education_2Group
 /CONTRAST (education_2Group)=Indicator(1)
 /SAVE=PGROUP
 /CLASSPLOT
 /PRINT=GOODFIT CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).
*_____

_____.
```

*Research Question 2g. What antecedents and mediators in the conceptual model predict decision outcomes?.

```
*Decision Regret.
*Decedent Characteristics.
*Age.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER age2
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Gender.
REGRESSION
 /MISSING LISTWISE
```

```
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER decedent_gender2
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Income.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER income2_Group2
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Education.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER education2_2Group
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Decision Regret, Age, and Gender.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER age2 decedent_gender2
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).
*_____
__.
*Decisional Conflict.
*Age.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER age2
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Gender.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
```

```
 /METHOD=ENTER decedent_gender2
 /CONTRAST (decedent_gender2)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Income.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER income2_Group2
 /CONTRAST (income2_Group2)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Education.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER education2_2Group
 /CONTRAST (education2_2Group)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).
*_____.
*Family Member Characteristics.
*Decision Regret.
*Age.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER age
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Gender.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER gender
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Income.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER income_2Groups
```

```
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Education.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER education_2Group
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Religious Values.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER Reflected_Sqrt_Religious_Values
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).
*_____.
*Decisional Conflict.
*Age.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER age
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Gender.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER gender
 /CONTRAST (gender)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Income.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER income_2Groups
 /CONTRAST (income_2Groups)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Education.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER education_2Group
 /CONTRAST (education_2Group)=Indicator(1)
 /PRINT=CI(95)
```

```
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Religious Values.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER Reflected_Sqrt_Religious_Values
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

*Decisional Conflict, Age, and Education.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER age education_2Group
 /CONTRAST (education_2Group)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).
*_____.
*General Communication.
*Decision Regret.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER Dichotomized_QOCgen
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Age.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER age
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Gender.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER gender
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Income.
REGRESSION
 /MISSING LISTWISE
```

```
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER income_2Groups
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Education.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER education_2Group
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Religious Values.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER Reflected_Sqrt_Religious_Values
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Decisional Regret, Quality of General Communication, and Religious Values.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER Dichotomized_QOCgen Reflected_Sqrt_Religious_Values
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*_____.
*General Communication.
*Decisional Conflict.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER Dichotomized_QOCgen
 /CONTRAST (Dichotomized_QOCgen)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Age.
```

```
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER age
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Gender.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER gender
 /CONTRAST (gender)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Income.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER income_2Groups
 /CONTRAST (income_2Groups)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Education.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER education_2Group
 /CONTRAST (education_2Group)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Religious Values.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER Reflected_Sqrt_Religious_Values
 /PRINT=GOODFIT CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

*Decisional Conflict, General Communication, and Age.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
 /METHOD=ENTER Dichotomized_QOCgen age
 /CONTRAST (Dichotomized_QOCgen)=Indicator(1)
 /PRINT=CI(95)
 /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).
*_____.
*EOL Communication.
*Decision Regret.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER QOCeol
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).
```

```
*Age.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER age
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Gender.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER gender
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Income.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER income_2Groups
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Education.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
 /METHOD=ENTER education_2Group
 /SCATTERPLOT=(*ZRESID ,*ZPRED)
 /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).

*Religious Values.
REGRESSION
 /MISSING LISTWISE
 /STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL
 /CRITERIA=PIN(.05) POUT(.10)
 /NOORIGIN
 /DEPENDENT Sqrt_Regret
```

```
  /METHOD=ENTER Reflected_Sqrt_Religious_Values
  /SCATTERPLOT=(*ZRESID ,*ZPRED)
  /RESIDUALS HISTOGRAM(ZRESID) NORMPROB(ZRESID).
*—————————————————————————————————————.
*EOL Communication.
*Decisional Conflict.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
  /METHOD=ENTER QOCeol
  /PRINT=CI(95)
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Age.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
  /METHOD=ENTER age
 /PRINT=GOODFIT CI(95)
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Gender.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
  /METHOD=ENTER gender
 /PRINT=GOODFIT CI(95)
  /CONTRAST (gender)=Indicator(1)
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Income.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
  /METHOD=ENTER income_2Groups
 /PRINT=GOODFIT CI(95)
  /CONTRAST (income_2Groups)=Indicator(1)
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Education.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
  /METHOD=ENTER education_2Group
 /PRINT=GOODFIT CI(95)
  /CONTRAST (education_2Group)=Indicator(1)
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).

*Religious Values.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
  /METHOD=ENTER Reflected_Sqrt_Religious_Values
 /PRINT=GOODFIT CI(95)
  /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).

*Decisoinal Conflct, EOL Communication, and Age.
LOGISTIC REGRESSION VARIABLES Dichotomized_Conflict
  /METHOD=ENTER QOCeol age
  /PRINT=CI(95)
  /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).
```

Permissions
From: Annette O'Connor [Annette.OConnor@uottawa.ca]
Sent: Thursday, March 19, 2015 8:10 AM
To: Smith-Howell, Esther Renee
Subject: RE: Permission to Use Your Framework in a Dissertation

Dear Esther Renee Smith-Howell,

You have my permission to use our Decision Support Framework found in *Journal of Obstetric, Gynecologic, & Neonatal Nursing.* 2002;31(5):570-581
Best wishes on the successful completion of your dissertation.

Sincerely yours,

Annette O'Connor PhD FCAHSc FRSC
Emeritus Professor
Distinguished University Professor
University of Ottawa
School of Nursing
Faculty of Health Sciences

From: Smith-Howell, Esther Renee [mailto:esmithho@iu.edu]
Sent: March-18-15 5:52 PM
To: Annette O'Connor
Subject: RE: Permission to Use Your Framework in a Dissertation

Hi Dr. O'Connor,

I hope all is well! I am following up with an email I sent last week, requesting to use your framework as a part my dissertation. To comply with Indiana University's copyright permission guidelines, is it okay that I use the ODSF framework you that you featured in the manuscript listed below? I am grateful for your consideration and look forward to hearing from you!

O'Connor AM, Jacobsen MJ, Stacey D. An Evidence-Based Approach to Managing
        Women's Decisional Conflict.*Journal of Obstetric, Gynecologic, & Neonatal
        Nursing.* 2002; 31(5):570-581.
 V/R,
Esther

Esther R. Smith-Howell, RN, BSN
Training in Behavioral Nursing Research
Pre Doctoral Fellow
Indiana University School of Nursing
1111 Middle Drive
NU 345
Indianapolis, IN 46202
Tel: 863-604-5196
Email: esmithho@iu.edu
Website: http://lnkd.in/dJsbMEF

From: Smith-Howell, Esther Renee
Sent: Saturday, March 14, 2015 11:09 PM
To: annette.oconnor@uottawa.ca
Subject: Permission to Use Your Framework in a Dissertation

Dr. O'Connor,

Hello, my name is Esther Smith-Howell and I am a doctoral candidate at Indiana University School of Nursing, completing my dissertation entitled "End-of-Life Decision-Making among African Americans with Serious Illness." Specifically, I'm exploring the factors that influenced the decision-making for African Americans with serious illness and their families. The Indiana University Graduate School requires that I receive copyright permission to use any figures that I did not create myself.

I used your framework and aspects of patient-centered communication to develop a framework to guide research on African American end-of-life decision-making. I used several concepts of the ODSF that were relevant to my dissertation study and integrated them into the African American End-of-life Decision-making Conceptual Framework, including family member characteristics and decision outcomes (decision regret and decisional conflict). The African American End-of-life Decision-making Conceptual Framework was used to explain the influences of decision-making for bereaved African American family members of decedents with serious illness. I've attached my framework and yours, so that you can see how I used aspects of the ODSF to inform my research. The version of your framework that I cited in my dissertation comes from the manuscript listed below. To comply with Indiana University's copyright permission protocol, is it okay that I use the attached framework in my dissertation? I am grateful for your consideration and look forward to hearing from you!

O'Connor AM, Jacobsen MJ, Stacey D. An Evidence-Based Approach to Managing Women's Decisional Conflict. *Journal of Obstetric, Gynecologic, & Neonatal Nursing.* 2002; 31(5):570-581.

Very Respectfully,
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References

1. Hertzog MA. Considerations in determining sample size for pilot studies. *Research in Nursing & Health.* 2008;31(2):180-191.
2. Denise F. Polit & Cheryl Tatano Beck. *Nursing Research: Generating and assessing evidence for nursing practice.* 8th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2008.
3. King M, Jones L, Barnes K, et al. Measuring spiritual belief: development and standardization of a Beliefs and Values Scale. *Psychological medicine.* 2006;36(3):417.
4. O'Connor A. Decisional Conflict Scale. 1993; www.ohri.ca/decisionaid. Accessed 5/1/11, 2011.
5. O'Connor A. Decision Regret Scale. 2003; www.ohri.ca/decisonaid. Accessed 5/1/11, 2011.
6. Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. *Medical Decision Making.* Jul-Aug 2003;23(4):281-292.
7. Engelberg R, Downey L, Curtis JR. Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care. *Journal of Palliative Medicine.* Oct 2006;9(5):1086-1098.
8. O'Connor AM JM. *Decisional Conflict: Assessing and Supporting Patients Experiencing Uncertainty About Decisions Affecting their Health.* 2003.
9. Murray M. MT, Fiset V., O'Connor AM, Jacobsen M.,. Decision support: helping patients and families to find a balance at the end of life. *International journal of Palliative Nursing.* 2004;10(6):8.
10. Sandelowski M. Sample-Size in Qualitative Research. *Research in Nursing & Health.* Apr 1995;18(2):179-183.
11. Sandelowski M. Whatever happened to qualitative description? *Research in Nursing & Health.* Aug 2000;23(4):334-340.
12. Kuzel AJ. Sampling in qualitative inquiry. In: Crabtree BF, Miller WL, eds. *Doing qualitative research.*: Thousand Oaks, CA, US: Sage Publications, Inc; 1992:31-44.
13. Cohen D CB. Qualitative Research Guidelines Project. 2006; http://www.qualres.org/HomeSemi-3629.html. Accessed 7/23/2011, 2011.
14. Nancy Burns & Susan K. Grove. *The Practice of Nursing Research: Appraisal, synthesis, and generation of evidence.* 6th ed. St. Louis, MO: saunders Elsevier; 2009.
15. Altheide DL. Ethnographic content analysis. *Qualitative Sociology.* 1987;10:65-77.
16. Morgan DL. Qualitative content analysis: a guide to paths not taken. *Qualitative Health Research.* Feb 1993;3(1):112-121.
17. Elo S, Kyngas H. The qualitative content analysis process. *Journal of Advanced Nursing.* Apr 2008;62(1):107-115.
18. Sandelowski M. Focus on Qualitative Methods - Qualitative-Analysis - What It Is and How to Begin. *Research in Nursing & Health.* Aug 1995;18(4):371-375.
19. Campbell CL, Williams IC, Orr T. Factors that impact end-of-life decision making in African Americans with advanced cancer. *Journal of Hospice & Palliative Nursing.* 2010;12(4):214-224.
1. Institute of Medicine, ed *Approaching death: Improving care at the end of life.* Washington, D.C.: National Academy Press; 1997.
2. National Institutes of Health. National Institutes of Health State-of-the-Science Conference: Statement on Improving End-of-Life Care. Dec 6-8, 2004.

3. National Institute of Nursing Research. Strategic Plan. In: Research NIoHNIoN, ed. Bethesda, MD2006.

4. American Cancer Society. *Cancer Facts & Figures for African Americans 2013-2014,.* 2013.

5. Centers for Disease Control and Prevention. Coronary Heart Disease and Stroke Deaths — United States, 2009. 2013; http://www.cdc.gov/mmwr/preview/mmwrhtml/su6203a26.htm?s_cid=su6203a26_w. Accessed March 9, 2015, 2015.

6. Lesage P, Portenoy RK. Ethical challenges in the care of patients with serious illness. *Pain Medicine.* 2001;2(2):121-130.

7. Smith TJ, Schnipper LJ. The American Society of Clinical Oncology program to improve end-of-life care. *Journal of Palliative Medicine.* 1998;1(3):221-230.

8. National Institute of Health. FACT SHEET - End-of-Life. 2010; http://report.nih.gov/NIHfactsheets/ViewFactSheet.aspx?csid=40&key=E#E. Accessed June 6, 2011.

9. Wright AA, Zhang BH, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Jama-Journal of the American Medical Association.* 2008;300(14):1665-1673.

10. Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. Comparing hospice and nonhospice patient survival among patients who die within a three-year window. *Journal of Pain and Symptom Management.* 2007;33(3):238-246.

11. Temel JS, Greer JA, Muzikansky A, et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *New England Journal of Medicine.* 2010;363(8):733-742.

12. Loggers ET, Maciejewski PK, Paulk E, et al. Racial Differences in Predictors of Intensive End-of-Life Care in Patients With Advanced Cancer. *Journal of Clinical Oncology.* 2009;27(33):5559-5564.

13. Earle CC, Neville BA, Landrum MB, Ayanian JZ, Block SD, Weeks JC. Trends in the aggressiveness of cancer care near the end of life. *Journal of Clinical Oncology.* 2004;22(2):315-321.

14. McKinley ED, Garrett JM, Evans AT, Danis M. Differences in end-of-life decision making among black and white ambulatory cancer patients. *Journal of General Internal Medicine.* 1996;11(11):651-656.

15. Ludke RL, Smucker DR. Racial differences in the willingness to use hospice services. *Journal of Palliative Medicine.* 2007;10(6):1329-1337.

16. Mazanec PM, Daly BJ, Townsend A. Hospice Utilization and End-of-Life Care Decision Making of African Americans. *American Journal of Hospice & Palliative Medicine.* 2010;277(8):560-566.

17. Organization NHaPC. *NHPCO Facts and Figures: Hospice Care in America.* Alexandria, VA2012.

18. Centers for Disease Control and Prevention. Minority Health. *Black or African American Populations* 2013; http://www.cdc.gov/minorityhealth/populations/REMP/black.html. Accessed September 16, 2013, 2013.

19. National Hospice and Palliative Care Organization. NHPCO Facts and Figures: Hospice Care in America. 2010.

20. Williams SW, Hanson LC, Boyd C, et al. Communication, decision making, and cancer: what African Americans want physicians to know. *Journal of Palliative Medicine.* 2008;11(9):1221-1226.

21. Moore CD. Communication issues and advance care planning. *Semin Oncol Nurs.* 2005;21(1):11-19.

22. Mularski RA, Dy SM, Shugarman LR, et al. A Systematic Review of Measures of End-of-Life Care and Its Outcomes. *Health services research.* 2007;42(5):1848-1870.

23. IOM (Institute of Medicine). *Dying in America: Improving quality and honoring individual preferences near the end of life. .* Washington, DC: The National Academies Press.2014.

24. Epstein RM Street RL Jr. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. Bethesda, MD 2007: National Cancer Institute, NIH Publication No. 07-6225,; 2007.

25. O'Connor AM. Ottawa Decision Support Framework to Address Decisional Conflict. 2006; www.ohri.ca/decisionaid.

26. Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered communication in patient-physician consultations: Theoretical and practical issues. *Social Science & Medicine.* 2005;61(7):1516-1528.

27. Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered communication in Patient–Physician consultations: Theoretical and practical issues. *Social Science & Medicine.* 2005;61(7):1516-1528.

28. The Joint Commission. The Joint Commission: Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals. Oakbrook Terrace, IL2010.

29. The Institute for Patient- and Family-Centered Care. Frequently Asked Questions: What is patient- and family-centered health care? 2013. Accessed September 10, 2013, 2013.

30. Tschann JM, Kaufman SR, Micco GP. Family involvement in end-of-life hospital care. *Journal of the American Geriatrics Society.* 2003;51(6):835-840.

31. Waters CM. Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. *Qualitative Health Research.* 2001;11(3):385-398.

32. Shrank WH, Kutner JS, Richardson T, Mularski RA, Fischer S, Kagawa-Singer M. Focus group findings about the influence of culture on communication preferences in end-of-life care. *Journal of General Internal Medicine.* 2005;20(8):703-709.

33. Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. EThnicity and attitudes toward patient autonomy. *JAMA.* 1995;274(10):820-825.

34. Campbell CL, Williams IC, Orr T. Factors that impact end-of-life decision making in African Americans with advanced cancer. *Journal of Hospice & Palliative Nursing.* 2010;12(4):214-224.

35. Hines SC, Glover JJ, Holley JL, Babrow AS, Badzek LA, Moss AH. Dialysis patients' preferences for family-based advance care planning. *Annals of Internal Medicine.* 1999;130(10):825-828.

36. Covinsky KE, Fuller JD, Yaffe K, et al. Communication and decision-making in seriously ill patients: findings of the SUPPORT project. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Journal of the American Geriatrics Society.* 2000;48(5 Suppl):S187-193.

37. Layde PM, Beam CA, Broste SK, et al. Surrogates' predictions of seriously ill patients' resuscitation preferences. *Archives of Family Medicine.* 1995;4(6):518-523.

38. Uhlmann RF, Pearlman RA, Cain KC. Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *Journal of Gerontology.* 1988;43(5):M115-M121.

39. Seckler AB, Meier DE, Mulvihill M, Cammer Paris BE. Substituted Judgment: How Accurate Are Proxy Predictions? *Annals of Internal Medicine.* 1991;115(2):92.

40. Hofmann JC, Wenger NS, Davis RB, et al. Patient preferences for communication with physicians about end-of-life decisions. *Annals of Internal Medicine.* 1997;127(1):1-&.

41. Shmerling R, Bedell S, Lilienfeld A, Delbanco T. Discussing cardiopulmonary resuscitation. *Journal of General Internal Medicine.* 1988;3(4):317-321.

42. Hite CA. THE DO-NOT-RESUSCITATE DECISION: THE CONTEXT, PROCESS, AND CONSEQUENCES OF DNR ORDERS. *Death Studies.* 2000;24(4):307-323.

43. Hall RI, Rocker GM. End-of-Life Care in the ICUTreatments Provided When Life Support Was or Was Not Withdrawn. *CHEST Journal.* 2000;118(5):1424-1430.

44. Smedira NG, Evans BH, Grais LS, et al. Withholding and withdrawal of life support from the critically ill. *New England Journal of Medicine.* 1990;322(5):309-315.

45. Hanson LC, Danis M, Mutran E, Keenan NL. Impact of patient incompetence on decisions to use or withhold life-sustaining treatment. *The American Journal of Medicine.* 1994;97(3):235-241.

46. Azoulay E, Pochard F, Chevret S, et al. Half the family members of intensive care unit patients do not want to share in the decision-making process: a study in 78 French intensive care units. *Critical Care Medicine.* 2004;32(9):1832-1838.

47. Gries CJ, Cuitis JR, Wall RJ, Engelberg RA. Family member satisfaction with end-of-life decision making in the ICU. *Chest.* 2008;133(3):704-712.

48. O'Connor A. Decision Regret Scale. 2003; www.ohri.ca/decisonaid. Accessed 5/1/11, 2011.

49. O'Connor A. Decision Self-Efficacy Scale. 2002; www.ohri.ca/decisionaid. Accessed 5/1/11, 2011.

50. O'Connor A. Decisional Conflict Scale. 1993; www.ohri.ca/decisionaid. Accessed 5/1/11, 2011.

51. O'Connor AM, Drake ER, Fiset V, Graham ID, Laupacis A, Tugwell P. The Ottawa patient decision aids. *Eff Clin Pract.* 1999;2(4):163-170.

52. King M, Jones L, Barnes K, et al. Measuring spiritual belief: development and standardization of a Beliefs and Values Scale. *Psychological medicine.* 2006;36(3):417.

53. O'Connor AM, Tugwell P, Wells GA, et al. Randomized trial of a portable, self-administered decision aid for postmenopausal women considering long-term preventive hormone therapy. *Medical Decision Making.* 1998;18(3):295-303.

54. O'Connor AM, Jacobsen MJ, Stacey D. An Evidence-Based Approach to Managing Women's Decisional Conflict. *Journal of Obstetric, Gynecologic, & Neonatal Nursing.* 2002;31(5):570-581.

55. O'Connor A, Jacobsen MJ, Stacey D. An evidence based approach to managing women's decisional conflict. *J Obstet Gynecol Neonatal Nurs.* 2002;31(5):570-581.

56. O'Connor AM. Validation of a decisional conflict scale. *Medical Decision Making.* 1995;15:25-30.

57. O'Connor AM. *Decisional conflict.* The CV Mosby Company, Toronto; 1997.

58. Murray M. MT, Fiset V., O'Connor AM, Jacobsen M.,. Decision support: helping patients and families to find a balance at the end of life. *International journal of Palliative Nursing.* 2004;10(6):8.

59. Tattersall MH, Butow PN, Clayton JM. Insights from cancer patient communication research. *Hematology/oncology clinics of North America.* 2002;16(3):731-743.

60. de Haes H, Teunissen S. Communication in palliative care: a review of recent literature. *Current Opinion in Oncology.* 2005;17(4):345-350.

61. Curtis JR, Patrick DL, Shannon SE, Treece PD, Engelberg RA, Rubenfeld GD. The family conference as a focus to improve communication about end-of-life care in the intensive care unit: opportunities for improvement. *Critical care medicine.* 2001;29(2):N26-N33.

62. Murray M, O'Connor A, Stacey D, Wilson K. Efficacy of a training intervention on the quality of practitioners' decision support for patients deciding about place of care at the end of life: A randomized control trial: Study protocol. *BMC Palliat Care.* 2008;7(1):1-9.

63. Monod S, Theologian ER, MM SRM, Büla CJ. Instruments measuring spirituality in clinical research: a systematic review. *Journal of General Internal Medicine.* 2011;26(11):1345-1357.

64. Allport GW, Ross JM. Personal religious orientation and prejudice. *Journal of Personality and Social Psychology.* 1967;5(4):432.

65. Koenig H, Parkerson Jr GR, Meador KG. Religion index for psychiatric research. 1997.

66. Cross TL. Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed. 1989.

67. Thompson HS, Valdimarsdottir HB, Winkel G, Jandorf L, Redd W. The Group-Based Medical Mistrust Scale: psychometric properties and association with breast cancer screening. *Preventive Medicine.* 2004;38(2):209-218.

68. Engelberg R, Downey L, Curtis JR. Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care. *Journal of Palliative Medicine.* 2006;9(5):1086-1098.

69. McGraw-Hill Concise Dictionary of Modern Medicine. patient-physician relationship. 2002; http://medical-dictionary.thefreedictionary.com/patient-physician+relationship. Accessed September 10 2013, 2013.

70. Association AM. Opinion 2.20 - Withholding or Withdrawing Life-Sustaining Medical Treatment. 2013.

71. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, Second Edition. Pittsburg, PA: National Consensus Project for Quality Palliative Care; 2009.

72. National Institute of Nursing Research. Palliative Care. Bethesda, MD2009:16.

73. Joyce V. Zerwekh. *Nursing Care at the End of Life: Palliative Care for Patients and Families.* Philadelphia, PA: F. A. Davis Company; 2006.

74. Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. *Medical Decision Making.* 2003;23(4):281-292.

75. Shavers VL, Lynch CF, Burmeister LF. Racial differences in factors that influence the willingness to participate in medical research studies. *Annals of Epidemiology.* 2002;12(4):248-256.

76. Gavaghan H. Clinical trials face lack of minority group volunteers. *Nature.* 1995;373(6511):178.

77. Shavers-Hornaday VL, Lynch CF, Burmeister LF, Torner JC. Why are African Americans under-represented in medical research studies? Impediments to participation. *Ethnicity & health.* 1997;2(1-2):31-45.

78. Millon-Underwood SPDRNESPD, Margaret Davis RNMSN. Determinants of participation in state-of-the-art cancer prevention, early detection/screening, and treatment trials among African-Americans. *Cancer Nursing.* 1993;16(1):25-33.

79. Schouten BC, Meeuwesen L. Cultural differences in medical communication: a review of the literature. *Patient Educ Couns.* 2006;64(1-3):21-34.

80. Hallenbeck JL. Intercultural differences and communication at the end of life. *Prim Care.* 2001;28(2):401-413.

81. Wallace MP, Weiner JS, Pekmezaris R, et al. Physician cultural sensitivity in African American advance care planning: a pilot study. *Journal of Palliative Medicine.* 2007;10(3):721-727.

82. Crawley LM. Racial, cultural, and ethnic factors influencing end-of-life care. *Journal of Palliative Medicine.* 2005;8 Suppl 1:S58-69.

83. Tulsky JA, Cassileth BR, Bennett CL. The effect of ethnicity on ICU use and DNR orders in hospitalized AIDS patients. *Journal of Clinical Ethics.* 1997;8(2):150-157.

84. Searight HR, Gafford J. Cultural diversity at the end of life: issues and guidelines for family physicians. *American Family Physician.* 2005;71(3):515-522.

85. Krakauer EL, Crenner C, Fox K. Barriers to optimum end-of-life care for minority patients. *Journal of the American Geriatrics Society.* 2002;50(1):182-190.

86. Steinhauser AE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *Jama-Journal of the American Medical Association.* 2000;284(19):2476-2482.

87. Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine.* 1999;48(12):1779-1789.

88. Torke AM, Garas NS, Sexson W, Branch WT. Medical care at the end of life: views of African American patients in an urban hospital. *Journal of Palliative Medicine.* 2005;8(3):593-602.

89. Winston CA, Leshner P, Kramer J, Allen G. Overcoming barriers to access and utilization of hospice and palliative care services in African-American communities. *Omega-Journal of Death and Dying.* 2004;50(2):151-163.

90. Johnson KS, Kuchibhatla M, Tulsky AA. What explains racial differences in the use of advance directives and attitudes toward hospice care? *Journal of the American Geriatrics Society.* 2008;56(10):1953-1958.

91. Gamble VN. A LEGACY OF DISTRUST - AFRICAN-AMERICANS AND MEDICAL-RESEARCH. *American Journal of Preventive Medicine.* 1993;9(6):35-38.

92. Gamble VN. Under the shadow of Tuskegee: African Americans and health care. *American Journal of Public Health.* 1997;87(11):1773-1778.

93. Smedley BD, Stith AY, Nelson AR, Institute of Medicine . Committee on U, Eliminating R, Ethnic Disparities in Health C. Unequal treatment confronting racial and ethnic disparities in health care. 2003; http://www.myilibrary.com?id=18405.

94. Tucker RT. Patient Self-Determination Act - an African-American Perspective. *Cambridge Quarterly of Healthcare Ethics.* 1994;3(3):417-419.

95.   Johnson KS, Elbert-Avila KI, Tulsky JA. The influence of spiritual beliefs and practices on the treatment preferences of African Americans: A review of the literature. *Journal of the American Geriatrics Society.* 2005;53(4):711-719.

96.   Reynolds PP. Hospitals and civil rights, 1945-1963: The case of Simkins v Moses H Cone Memorial Hospital. *Annals of Internal Medicine.* 1997;126(11):898-906.

97.   Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA : the journal of the American Medical Association.* 1998;279(21):1709-1714.

98.   Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist.* 2005;45(5):634-641.

99.   Harrington SE, Smith TJ. The role of chemotherapy at the end of life: "When is enough, enough?". *Jama-Journal of the American Medical Association.* 2008;299(22):2667-E2661.

100.   Siminoff LA, Fetting JH, Abeloff MD. DOCTOR-PATIENT COMMUNICATION ABOUT BREAST-CANCER ADJUVANT THERAPY. *Journal of Clinical Oncology.* 1989;7(9):1192-1200.

101.   Perloff RM, Bonder B, Ray GB, Ray EB, Siminoff LA. Doctor-patient communication, cultural competence, and minority health - Theoretical and empirical perspectives. *American Behavioral Scientist.* 2006;49(6):835-852.

102.   Jenkins C, Lapelle N, Zapka JG, Kurent JE. End-of-life care and African Americans: voices from the community. *Journal of Palliative Medicine.* 2005;8(3):585-592.

103.   Morrison RS, Zayas LH, Mulvihill M, Baskin SA, Meier DE. Barriers to completion of health care proxies - An examination of ethnic differences. *Archives of Internal Medicine.* 1998;158(22):2493-2497.

104.   Zapka JG, DesHarnais S. Care at the end of life: Focus on communication and race. *Journal of Aging and Health.* 2006;18(6):791-813.

105.   Smith AK, Davis RB, Krakauer EL. Differences in the quality of the patient-physician relationship among terminally ill African-American and white patients: impact on advance care planning and treatment preferences. *Journal of General Internal Medicine.* 2007;22(11):1579-1582.

106.   Cooper-Patrick L, Gallo JJ, Gonzales JJ, et al. Race, gender, and partnership in the patient-physician relationship. *JAMA : the journal of the American Medical Association.* 1999;282(6):583-589.

107.   Torke AM, Alexander GC, Lantos J, Siegler M. The physician-surrogate relationship. *Archives of Internal Medicine.* 2007;167(11):1117-1121.

108.   Gattellari M, Butow PN, Tattersall MH, Dunn SM, MacLeod CA. Misunderstanding in cancer patients: why shoot the messenger? *Ann Oncol.* 1999;10(1):39-46.

109.   von Gunten CF, Muir JC. Palliative medicine: An emerging field of specialization. *Cancer Investigation.* 2000;18(8):761-767.

110.   Ragan SL. *Communication as Comfort: Multiple Voices in Palliative Care.* 2008.

111.   World Health Organization. WHO Definition of Palliative Care. 2011; http://www.who.int/cancer/palliative/definition/en/.

112.   Center to Advance Palliative Care. Program Model Options Chart. 2014; http://www.capc.org/building-a-hospital-based-palliative-care-program/designing/characteristics/program-model-chart. Accessed May 28, 2014, 2014.

113.   The Center to Advance Palliative Care. Palliative Care vs. Other Services. 2011; http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc/designing/presenting-plan/pc_vs_other/.

114. Bosma H, Apland L, Kazanjian A. Cultural conceptualizations of hospice palliative care: more similarities than differences. *Palliative Medicine.* 2010;24(5):510-522.
115. Baker R, Wu AW, Teno JM, et al. Family satisfaction with end-of-life care in seriously ill hospitalized adults. *Journal of the American Geriatrics Society.* 2000;48(5):S61-S69.
116. Curtis JR, Patrick DL, Caldwell ES, Collier AC. Why Don't Patients and Physicians Talk About End-of-Life Care?: Barriers to Communication for Patients With Acquired Immunodeficiency Syndrome and Their Primary Care Clinicians. *Arch Intern Med.* 2000;160(11):1690-1696.
117. Doka KJaT, Amy S,. *Living with Grief: Diversity and End-of-Life Care.* Hospice Foundation of America; 2009.
118. Musa BA, Domatob JK. *Communication, Culture, and Human Rights in Africa.* University Press of America; 2012.
119. Mitchell BL, Mitchell LC. Review of the Literature on Cultural Competence and End-of-Life Treatment Decisions: The Role of the Hospitalist. *Journal of the National Medical Association.* 2009;101(9):920-926.
120. Kim Y, Pavlish C, Evangelista LS, Kopple JD, Phillips LR. Racial/ethnic differences in illness perceptions in minority patients undergoing maintenance hemodialysis. *Nephrology Nursing Journal.* 2012;39(1):39.
121. Galanti G-A. *Caring for patients from different cultures.* University of Pennsylvania Press; 2008.
122. Hinton MD. Leading Historically Black Church Congregations. In: Callahan SH, ed. *Religious Leadershp: A reference book handbook*. Thousand Oaks, CA: Sage Publications; 2013.
123. Encyclopædia Britannica. African Americans. *Encyclopædia Britannica*2013.
124. Britannica E. African Americans. 2013.
125. Light D, Keller S, Calhoun C. *Sociology.* McGraw-Hill Companies; 1989.
126. Raboteau AJ. *Slave Religion: The "Invisible Institution" in the Antebellum South.* Oxford University Press, USA; 2004.
127. Hammond PE. Religion and the Persistence of Identity. *Journal for the Scientific Study of Religion.* 1988;27(1):1-11.
128. Marable M. *Race, Reform, and Rebellion: The Second Reconstruction in Black America, 1945-1990.* University Press of Mississippi Jackson; 1991.
129. Young C. *Black experience: Analysis and synthesis.* Leswing Press; 1972.
130. Berry MF, Blassingame JW. *Long Memory: The Black Experience in America.* OUP USA; 1982.
131. Washington H. *Medical Apartheid.* New York, NY: Harlem Moon, Broadway Books; 2006.
132. Brandt AM. Racism and research: the case of the Tuskegee syphilis study. *Hastings Center Report.* 1978;8(6):21-29.
133. Edmonds BT. Moving Beyond the Impasse Discussing Death and Dying With African American Patients. *Obstetrics and Gynecology.* 2011;117(2):383-387.
134. Encyclopædia Britannica. Tuskegee syphilis study. 2012; http://www.britannica.com/EBchecked/topic/610607/Tuskegee-syphilis-study.
135. <Bullock - Promoting Advance Directives among African Americans - A Faith-Based Model.pdf>.
136. Reese DJ, Ahern RE, Nair S, Joleen D, Warren C. Hospice access and use by African Americans: Addressing cultural and institutional barriers through participatory action research. *Social Work.* 1999;44(6):549-559.

137. Born W, Greiner KA, Sylvia E, Butler J, Ahluwalia JS. Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *J Palliat Med.* 2004;7(2):247-256.

138. WERTH JL, BLEVINS D, TOUSSAINT KL, DURHAM MR. The Influence of Cultural Diversity on End-of-life Care and Decisions. *American Behavioral Scientist.* 2002;46(2):204-219.

139. Crawley LM. Palliative Care in African American Communities. *Journal of Palliative Medicine.* 2002;5(5):775-779.

140. Juckett G. Cross-cultural medicine. *Am Fam Physician.* 2005;72(11):2267-2274.

141. Tong E, McGraw SA, Dobihal E, Baggish R, et al. What is a good death? Minority and non-minority perspectives. *Journal of Palliative Care.* 2003;19(3):168-175.

142. Lincoln CE, Mamiya LH. *The Black Church in the African American Experience.* Duke University Press; 1990.

143. Baumeister RF. *Meanings of Life.* Guilford Publication; 1991.

144. Emmons RA, Paloutzian RF. The psychology of religion. *Annu Rev Psychol.* 2003;54:377-402.

145. McIntosh DN. Religion-as-Schema, With Implications for the Relation Between Religion and Coping. *International Journal for the Psychology of Religion.* 1995;5(1):1-16.

146. Pargament KI, Koenig HG, Tarakeshwar N, Hahn J. Religious struggle as a predictor of mortality among medically ill elderly patients - A 2-year longitudinal study. *Archives of Internal Medicine.* 2001;161(15):1881-1885.

147. Bryant S, Rakowski W. Predictors of Mortality among Elderly African-Americans. *Research on Aging.* 1992;14(1):50-67.

148. Neighbors HW, Musick MA, Williams DR. The African American minister as a source of help for serious personal crises: bridge or barrier to mental health care? *Health Education & Behavior.* 1998;25(6):759-777.

149. Du Bois WEB. The Study of the Negro Problems. *The Annals of the American Academy of Political and Social Science.* 1898;Vol. XI,:pp.1-23.

150. McKinzie Lewis. The African American Church. In: Smith-Howell E, ed. Description of the African American Church ed. Indianapolis, IN2013.

151. Mitchell HH. *Black Church beginnings: The long-hidden realities of the first years.* Wm. B. Eerdmans Publishing; 2004.

152. Moore T. The African-American church: A source of empowerment, mutual help, and social change. *Prevention in Human Services.* 1991;10(1):147-167.

153. Ellison CG, Hummer RA, Cormier S, Rogers RG. Religious Involvement and Mortality Risk among African American Adults. *Research on Aging.* 2000;22(6):630-667.

154. Griffin LW, Bratton LB. Fewer black kidney donors: what's the problem? *Social work in health care.* 1996;22(2):19-42.

155. Taylor RJ, Thornton MC, Chatters LM. Black Americans' Perceptions of the Sociohistorical Role of the Church. *Journal of Black Studies.* 1987;18(2):123-138.

156. Veroff J, Kulka RA, Douvan EAM. *Mental health in America: patterns of help-seeking from 1957 to 1976.* Basic Books; 1981.

157. Mollica RF, Streets FJ, Boscarino J, Redlich FC. A community study of formal pastoral counseling activities of the clergy. *The American journal of psychiatry.* 1986.

158. Beit-Hallahmi B, Argyle M. *The Psychology of Religious Behaviour, Belief and Experience.* ROUTLEDGE CHAPMAN & HALL; 1997.

159. Kotarba JA. Perceptions of death, belief systems and the process of coping with chronic pain. *Social Science & Medicine.* 1983;17(10):681-689.

160. Hamel RP, Lysaught MT. Choosing palliative care: do religious beliefs make a difference? *Journal of Palliative Care.* 1994.

161. Franklin MD, Schlundt DG, McClellan LH, et al. Religious fatalism and its association with health behaviors and outcomes. *American Journal of Health Behavior.* 2007;31(6):563-572.

162. Taylor RJ, Chatters LM. Religious life. 1991.

163. Ferraro KF, Koch JR. Religion and health among black and white adults: Examining social support and consolation. *Journal for the Scientific Study of Religion.* 1994:362-375.

164. Mansfield CJ, Mitchell J, King DE. The doctor as God's mechanic? Beliefs in the Southeastern United States. *Social Science & Medicine.* 2002;54(3):399-409.

165. Potts RG. Spirituality and the experience of cancer in an African-American community: implications for psychosocial oncology. *Journal of Psychosocial Oncology.* 1996;14(1):1-19.

166. Murphy ST, Palmer JM, Azen S, Frank G, Michel V, Blackhall LJ. Ethnicity and advance care directives. *Journal of Law, Medicine & Ethics.* 1996;24(2):108-117.

167. Hauser JM, Kleefield SF, Brennan TA, Fischbach RL. Minority populations and advance directives: Insights from a focus group methodology. *Cambridge Quarterly of Healthcare Ethics.* 1997;6(1):58-71.

168. Conway K. Coping with the stress of medical problems among black and white elderly. *The International Journal of Aging and Human Development.* 1985;21(1):39-48.

169. Bearon LB, Koenig HG. Religious cognitions and use of prayer in health and illness. *The Gerontologist.* 1990;30(2):249-253.

170. Kaplan MS, Marks G, Mertens SB. Distress and coping among women with HIV infection: Preliminary findings from a multiethnic sample. *American Journal of Orthopsychiatry.* 1997;67(1):80-91.

171. Meredith KL, Jeffe DB, Mundy LM, Fraser VJ. Sources influencing patients in their HIV medication decisions. *Health Education & Behavior.* 2001;28(1):40-50.

172. King DE, Bushwick B. Beliefs and attitudes of hospital inpatients about faith healing and prayer. *The Journal of family practice.* 1994.

173. Bushwick B, King DE. Beliefs and attitudes of hospital inpatients about faith healing and prayer. *Journal of Family Practice.* Vol 391994:349+.

174. Heeren O, Menon AS, Raskin A, Ruskin P. Religion and end of life treatment preferences among geriatric patients. *International Journal of Geriatric Psychiatry.* 2001;16(2):203-208.

175. Numbers RL, Amundsen DW. *Caring and curing: Health and medicine in the Western religious traditions.* Johns Hopkins University Press; 1998.

176. Sullivan LE. *Healing and restoring: Health and medicine in the world's religious traditions.* Macmillan; 1989.

177. Dupree CY. The attitudes of black Americans toward advance directives. *J Transcult Nurs.* 2000;11(1):12-18.

178. www.history.com. Civil Rights Movement. 2013; http://www.history.com/topics/civil-rights-movement, 2013.

179. American Cancer Society. *Cancer Facts & Figures for African Americans 2013-2014.* Atlanta: American Cancer Society;2013.

180. Nelson A. Unequal treatment: confronting racial and ethnic disparities in health care. *Journal of the National Medical Association.* 2002;94(8):666.

181. Potosky AL, Breen N, Graubard BI, Parsons PE. The association between health care coverage and the use of cancer screening tests: results from the 1992 National Health Interview Survey. *Medical Care.* 1998;36(3):257-270.

182. Perloff JD, Kletke PR, Fossett JW, Banks S. Medicaid participation among urban primary care physicians. *Medical Care.* 1997;35(2):142-157.

183. Smedley BD, Stith AY, Nelson AR. *Unequal treatment: confronting racial and ethnic disparities in health care (with CD).* National Academies Press; 2009.

184. Watson SD. REINVIGORATING TITLE VI: DEFENDING HEALTH CARE DISCRIMINATION--IT SHOULDN'T BE SO EASY. *Fordham L. Rev.* 1990;58:939-1353.

185. Noah B. Racial Disparities in the Delivery of Health Care. *San Diego Law Review.* 1998;35:135.

186. Schulman KA. The effect of race and sex on physicians' recommendations for cardiac catheterization (vol 340, pg 618, 1999). *New England Journal of Medicine.* 1999;340(14):1130-1130.

187. van Ryn M, Burke J. The effect of patient race and socio-economic status on physicians' perceptions of patients. *Social Science & Medicine.* 2000;50(6):813-828.

188. van Ryn M. Research on the provider contribution to race/ethnicity disparities in medical care. *Medical Care.* 2002;40(1):140-151.

189. Giles WH, Anda RF, Casper ML, Escobedo LG, Taylor HA. Race and sex differences in rates of invasive cardiac procedures in US hospitals. Data from the National Hospital Discharge Survey. *Arch Intern Med.* 1995;155(3):318-324.

190. Whittle J, Conigliaro J, Good CB, Lofgren RP. Racial Differences in the Use of Invasive Cardiovascular Procedures in the Department of Veterans Affairs Medical System. *New England Journal of Medicine.* 1993;329(9):621-627.

191. Cleeland CS, Gonin R, Baez L, Loehrer P, Pandya KJ. Pain and treatment of pain in minority patients with cancer. The Eastern Cooperative Oncology Group Minority Outpatient Pain Study. *Ann Intern Med.* 1997;127(9):813-816.

192. Lillie-Blanton M, Brodie M, Rowland D, Altman D, McIntosh M. Race, Ethnicity, and the Health Care System: Public Perceptions and Experiences. *Medical Care Research and Review.* 2000;57(4 suppl):218-235.

193. Kahn KL, Pearson ML, Harrison ER, et al. HEalth care for black and poor hospitalized medicare patients. *JAMA.* 1994;271(15):1169-1174.

194. Harris D, Andrews R, Elixhauser A. Racial and gender differences in use of procedures for black and white hospitalized adults. *Ethnicity & disease.* 1996;7(2):91-105.

195. Wenneker MB, Epstein AM. RACIAL INEQUALITIES IN THE USE OF PROCEDURES FOR PATIENTS WITH ISCHEMIC HEART-DISEASE IN MASSACHUSETTS. *Jama-Journal of the American Medical Association.* 1989;261(2):253-257.

196. Peterson ED, Shaw LK, DeLong ER, Pryor DB, Califf RM, Mark DB. Racial variation in the use of coronary-revascularization procedures - Are the differences real? Do they matter? *New England Journal of Medicine.* 1997;336(7):480-486.

197. Nelson SC, Hackman HW. Race matters: Perceptions of race and racism in a sickle cell center. *Pediatric blood & cancer.* 2013;60(3):451-454.

198. Carlisle DM, Leake BD, Shapiro MF. RACIAL AND ETHNIC-DIFFERENCES IN THE USE OF INVASIVE CARDIAC PROCEDURES AMONG CARDIAC PATIENTS IN LOS-ANGELES-COUNTY, 1986 THROUGH 1988. *American Journal of Public Health.* 1995;85(3):352-356.

199. Todd KH, Deaton C, D'Adamo AP, Goe L. Ethnicity and analgesic practice. *Ann Emerg Med.* 2000;35(1):11-16.

200. Engle VF, Fox-Hill E, Graney MJ. The experience of living-dying in a nursing home: self-reports of black and white older adults. *J Am Geriatr Soc.* 1998;46(9):1091-1096.

201. Anderson KO, Mendoza TR, Valero V, et al. Minority cancer patients and their providers: pain management attitudes and practice. *Cancer.* 2000;88(8):1929-1938.

202. Mack JW, Paulk ME, Viswanath K, Prigerson HG. Racial Disparities in the Outcomes of Communication on Medical Care Received Near Death. *Archives of Internal Medicine.* 2010;170(17):1533-1540.

203. American Cancer Society. Cancer Facts & Figures for African Americans 2011-2012. 2011.

204. Caralis PV, Davis B, Wright K, Marcial E. The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *J Clin Ethics.* 1993;4(2):155-165.

205. Savitt TL. The Use of Blacks for Medical Experimentation and Demonstration in the Old South. *The Journal of Southern History.* 1982;48(3):331-348.

206. Klessig J. THE EFFECT OF VALUES AND CULTURE ON LIFE-SUPPORT DECISIONS. *Western Journal of Medicine.* 1992;157(3):316-322.

207. Miller B, Campbell RT, Davis L, et al. Minority use of community long-term care services: A comparative analysis. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences.* 1996;51(2):S70-S81.

208. Cooper LA, Roter DL, Johnson RL, Ford DE, Steinwachs DM, Powe NR. Patient-centered communication, ratings of care, and concordance of patient and physician race. *Annals of Internal Medicine.* 2003;139(11):907-915.

209. Cooper LA, Beach MC, Johnson RL, Inui TS. Delving below the surface - Understanding how race and ethnicity influence relationships in health care. *Journal of General Internal Medicine.* 2006;21:S21-S27.

210. Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient-physician communication during medical visits. *American Journal of Public Health.* 2004;94(12):2084-2090.

211. Collins KS, Commonwealth F. *Diverse communities, common concerns : assessing health care quality for minority Americans : findings from the Commonwealth Fund 2001 health care quality survey.* [New York, N.Y.]: Commonwealth Fund; 2002.

212. Tulsky JA. Interventions to enhance communication among patients, providers, and families. *J Palliat Med.* 2005;8 Suppl 1:S95-102.

213. Doescher MP, Saver BG, Franks P, Fiscella K. Racial and ethnic disparities in perceptions of physician style and trust. *Arch Fam Med.* 2000;9(10):1156-1163.

214. LaVeist TA, Nickerson KJ, Bowie JV. Attitudes about racism, medical mistrust, and satisfaction with care among African American and white cardiac patients. *Med Care Res Rev.* 2000;57 Suppl 1:146-161.

215. Crawley LM, Ahn DK, Winkleby MA. Perceived medical discrimination and cancer screening behaviors of racial and ethnic minority adults. *Cancer Epidemiology Biomarkers & Prevention.* 2008;17(8):1937-1944.

216. Shavers VL, Brown ML. Racial and ethnic disparities in the receipt of cancer treatment. *J Natl Cancer Inst.* 2002;94(5):334-357.

217. Sonia Nazzario. Treating Doctors for Prejudice: Medical Schools Are Trying to Sensitize Students to 'Bedside Bias'. *Los Angeles Times.* 12/20/1990, 1990.

218. Silveira MJ, DiPiero A, Gerrity MS, Feudtner C. Patients' knowledge of options at the end of life - Ignorance in the face of death. *Jama-Journal of the American Medical Association.* 2000;284(19):2483-2488.

219. Casarett D, Crowley R, Stevenson C, Xie S, Teno J. Making difficult decisions about hospice enrollment: What do patients and families want to know? *Journal of the American Geriatrics Society.* 2005;53(2):249-254.

220. Degenholtz HB, Arnold RA, Meisel A, Lave JR. Persistence of racial disparities in advance care plan documents among nursing home residents. *Journal of the American Geriatrics Society.* 2002;50(2):378-381.

221. Allen RS, Allen JY, Hilgeman MM, DeCoster J. End-of-life decision-making, decisional conflict, and enhanced information: Race effects. *Journal of the American Geriatrics Society.* 2008;56(10):1904-1909.

222. Gerst K, Burr JA. Planning for end-of-life care - Black-White differences in the completion of advance directives. *Research on Aging.* 2008;30(4):428-449.

223. Hopp FP. Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elders: Results from a national study. *Gerontologist.* 2000;40(4):449-457.

224. Wicher CP, Meeker MA. What Influences African American End-of-life Preferences? *Journal of Health Care for the Poor and Underserved.* 2012;23(1):28-58.

225. Johnson KS, Kuchibhatla M, Tulsky JA. Racial Differences in Self-Reported Exposure to Information about Hospice Care. *Journal of Palliative Medicine.* 2009;12(10):921-927.

226. Taxis JC. Attitudes, Values, and Questions of African Americans Regarding Participation in Hospice Programs. *Journal of Hospice & Palliative Nursing.* 2006;8(2):77-85.

227. Peppercorn JM, Smith TJ, Helft PR, et al. American Society of Clinical Oncology Statement: Toward Individualized Care for Patients With Advanced Cancer. *Journal of Clinical Oncology.* 2011;29(6):755-760.

228. Quill TE. Initiating end-of-life discussions with seriously ill patients - Addressing the "elephant in the room". *Jama-Journal of the American Medical Association.* 2000;284(19):2502-2507.

229. Gordon NP, Shade SB. Advance directives are more likely among seniors asked about end-of-life care preferences. *Archives of Internal Medicine.* 1999;159(7):701.

230. Centers for Disease Control and Prevention/National Center for Health Statistics. Life Expectancy. [Website]. 2011; http://www.cdc.gov/nchs/fastats/lifexpec.htm. Accessed 6/27/11, 2011.

231. He Wan MS, Victoria A. Velkoff , Kimberly A. DeBarros,. 65+ in the United States: 2005. In: Bureau USC, ed. Washington, DC: U.S. Government Printing Office; 2005.

232. Edwards BK, Howe HL, Ries LAG, et al. Annual Report to the Nation on the status of cancer, 1973–1999, featuring implications of age and aging on U.S. cancer burden. *Cancer.* 2002;94(10):2766-2792.

233. Owens GM. Gender differences in health care expenditures, resource utilization, and quality of care. *Journal of Managed Care Pharmacy.* 2008;14(3):S2.

234. Bradley EH, Wetle T, Horwitz SM. The patient self-determination act and advance directive completion in nursing homes. *Archives of Family Medicine.* 1998;7:417-424.

235. Wenger NS, Kanouse DE, Collins RL, et al. End-of-life discussions and preferences among persons with HIV. *JAMA: The Journal of the American Medical Association.* 2001;285(22):2880-2887.

236. Ott BB. Advance directives: the emerging body of research. *American Journal of Critical Care.* 1999;8(1):514-519.

237. Rosnick CB, Reynolds SL. Thinking ahead: factors associated with executing advance directives. *Journal of Aging and Health.* 2003;15(2):409-429.

238. Cohen-Mansfield J, Droge JA, Billig N. Factors influencing hospital patients' preferences in the utilization of life-sustaining treatments. *The Gerontologist.* 1992;32(1):89-95.

239. Rurup ML, Onwuteaka-Philipsen BD, van der Heide A, van der Wal G, Deeg DJH. Frequency and determinants of advance directives concerning end-of-life care in The Netherlands. *Social Science & Medicine.* 2006;62(6):1552-1563.

240. Navaie-Waliser M, Feldman PH, Gould DA, Levine C, Kuerbis AN, Donelan K. When the caregiver needs care: the plight of vulnerable caregivers. *American Journal of Public Health.* 2002;92(3):409-413.

241. Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Affairs.* 1999;18(2):182-188.

242. National Alliance for Caregiving A. *Family caregiving in the U.S.: Findings from a national survey.* Washington, D.C.1997.

243. Emanuel EJ, Fairclough DL, Slutsman J, Alpert H, Baldwin D, Emanuel LL. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *New England Journal of Medicine.* 1999;341(13):956-963.

244. Phipps E, True G, Harris D, et al. Approaching the end of life: attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. *Journal of Clinical Oncology.* 2003;21(3):549-554.

245. Hornung CA, Eleazer GP, Strothers HS, et al. Ethnicity and decision-makers in a group of frail older people. *Journal of the American Geriatrics Society.* 1998;46(3):280-286.

246. Chen HB, Haley WE, Robinson BE, Schonwetter RS. Decisions for hospice care in patients with advanced cancer. *Journal of the American Geriatrics Society.* 2003;51(6):789-797.

247. Arora NK. Interacting with cancer patients: the significance of physicians' communication behavior. *Social Science & Medicine.* 2003;57(5):791-806.

248. Roter DL, Hall JA. Health education theory: an application to the process of patient-provider communication. *Health Education Research.* 1991;6(2):185-193.

249. Makoul G. Essential elements of communication in medical encounters: the Kalamazoo consensus statement. *Acad Med.* 2001;76(4):390-393.

250. Ridd M, Shaw A, Lewis G, Salisbury C. The patient-doctor relationship: a synthesis of the qualitative literature on patients' perspectives. *British Journal of General Practice.* 2009;59(561):268-275.

251. Ong LML, Dehaes J, Hoos AM, Lammes FB. DOCTOR-PATIENT COMMUNICATION - A REVIEW OF THE LITERATURE. *Social Science & Medicine.* 1995;40(7):903-918.

252. Hall JA, Horgan TG, Stein TS, Roter DL. Liking in the physician-patient relationship. *Patient Education and Counseling.* 2002;48(1):69-77.

253. Takayama T, Yamazaki Y, Katsumata N. Relationship between outpatients' perceptions of physicians' communication styles and patients' anxiety levels in a Japanese oncology setting. *Social Science & Medicine.* 2001;53(10):1335-1350.

254. Zachariae R, Pedersen CG, Jensen AB, Ehrnrooth E, Rossen PB, von der Maase H. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. *British Journal of Cancer.* 2003;88(5):658-665.

255. Henman MJ, Butow PN, Brown RF, Boyle F, Tattersall MHN. Lay constructions of decision-making in cancer. *Psycho-Oncology.* 2002;11(4):295-306.

256. Lee SJ, Back AL, Block SD, Stewart SK. Enhancing physician-patient communication. *Hematology / the Education Program of the American Society of Hematology. American Society of Hematology. Education Program.* 2002:464-483.

257. Wallace P. Improving palliative care through effective communication. *International journal of Palliative Nursing.* 2001;7(2):86-90.

258. Curtis JR, Wenrich MD, Carline JD, Shannon SE, Ambrozy DM, Ramsey PG. Understanding physicians' skills at providing end-of-life care - Perspectives of patients, families, and health care workers. *Journal of General Internal Medicine.* 2001;16(1):41-49.

259. Wenrich MD, Curtis JR, Shannon SE, Carline JD, Ambrozy DM, Ramsey PG. Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death. *Archives of Internal Medicine.* 2001;161(6):868-874.

260. Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. *European Journal of Cancer.* 1999;35(11):1592-1597.

261. Royak-Schaler R, Gadalla SM, Lemkau JP, Ross DD, Alexander C, Scott D. Family perspectives on communication with healthcare providers during end-of-life cancer care. *Oncology Nursing Forum.* 2006;33(4):753-760.

262. Sullivan AM, Lakoma MD, Matsuyama RK, Rosenblatt L, Arnold RM, Block SD. Diagnosing and discussing imminent death in the hospital: A secondary analysis of physician interviews. *Journal of Palliative Medicine.* 2007;10(4):882-893.

263. Hagerty RG, Butow PN, Ellis PA, et al. Cancer patient preferences for communication of prognosis in the metastatic setting. *Journal of Clinical Oncology.* 2004;22(9):1721-1730.

264. Zeelenberg M. The use of crying over spilled milk: A note on the rationality and functionality of regret. 1999.

265. Connolly T, Ordóñez LD, Coughlan R. Regret and responsibility in the evaluation of decision outcomes. *Organizational behavior and human decision processes.* 1997;70(1):73-85.

266. Gilovich T, Medvec VH. The experience of regret: what, when, and why. *Psychological review.* 1995;102(2):379.

267. Clark JA, Wray N, Brody B, Ashton C, Giesler B, Watkins H. Dimensions of quality of life expressed by men treated for metastatic prostate cancer. *Social Science & Medicine.* 1997;45(8):1299-1309.

268. Smith RD. Is Regret Theory an alternative basis for estimating the value of healthcare interventions? *Health Policy.* 1996;37(2):105-115.

269. Sawka CA, Goel V, Mahut CA, et al. Development of a patient decision aid for choice of surgical treatment for breast cancer. *Health Expectations.* 1998;1(1):23-36.

270. Creyer EH, Ross Jr WT. The development and use of a regret experience measure to examine the effects of outcome feedback on regret and subsequent choice. *Marketing Letters.* 1999;10(4):373-386.

271. Clark JA, Wray NP, Ashton CM. Living with treatment decisions: regrets and quality of life among men treated for metastatic prostate cancer. *Journal of Clinical Oncology.* 2001;19(1):72-80.

272. Montgomery LL, Tran KN, Heelan MC, Van Zee KJ, Massie MJ, Borgen PI. Issues of regret in women with contralateral prophylactic mastectomies. *Annals of Surgical Oncology.* 1999;6(6):546-552.

273. Janis IL, & Mann, L.,. *Decision Making: Psychological Analysis of Conflict, Choice, and Commitment.* New York, NY: The Free Press, A Division of Macmillan Publishing Co., Inc.; 1977.

274. Dolan JG, Frisina S. Randomized controlled trial of a patient decision aid for colorectal cancer screening. *Medical Decision Making.* 2002;22(2):125-139.

275. Davison BJ, Kirk P, Degner LF, Hassard TH. Information and patient participation in screening for prostate cancer. *Patient Education and Counseling.* 1999;37(3):255-263.

276. Morgan MW. A randomized trial of the Ischemic Heart Disease Shared Decision Making Program, an evaluation of a decision aid. 1997.

277. Song M-K, Sereika SM. An evaluation of the Decisional Conflict Scale for measuring the quality of end-of-life decision making. *Patient Education and Counseling.* 2006;61(3):397-404.

278. Eskenazi Health Palliative Care Program. About Eskenazi Health Palliative Care Program. 2014; http://www.eskenazihealth.edu/our-services/palliative-care-program/about. Accessed May 28, 2014, 2014.

279. Hertzog MA. Considerations in determining sample size for pilot studies. *Research in Nursing & Health.* 2008;31(2):180-191.

280. Denise F. Polit & Cheryl Tatano Beck. *Nursing Research: Generating and assessing evidence for nursing practice.* 8th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2008.

281. Razali NM, Wah YB. Power comparisons of shapiro-wilk, kolmogorov-smirnov, lilliefors and anderson-darling tests. *Journal of Statistical Modeling and Analytics.* 2011;2(1):21-33.

282. Keskin S. Comparison of several univariate normality tests regarding type I error rate and power of the test in simulation based small samples. *Journal of Applied Science Research.* 2006;2(5):296-300.

283. Mehmet M, Akin P. Type I error rate and power of three normality tests. *Information Technology Journal.* 2003.

284. Shapiro SS, Wilk MB. An Analysis of Variance Test for Normality (Complete Samples). *Biometrika.* 1965;52(3/4):591-611.

285. Cochran WG. The χ2 Test of Goodness of Fit. *The Annals of Mathematical Statistics.* 1952;23(3):315-345.

286. Ayres L, Kavanaugh K, Knafl KA. Within-case and across-case approaches to qualitative data analysis. *Qualitative health research.* 2003;13(6):871-883.

287. Sandelowski M. Whatever happened to qualitative description? *Research in Nursing & Health.* 2000;23(4):334-340.

288. Nancy Burns & Susan K. Grove. *The Practice of Nursing Research: Appraisal, synthesis, and generation of evidence.* 6th ed. St. Louis, MO: saunders Elsevier; 2009.

289. O'Connor AM JM. *Decisional Conflict: Assessing and Supporting Patients Experiencing Uncertainty About Decisions Affecting their Health.* 2003.

290. Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook.* Sage; 1994.

291. Cartwright JC, Hickman SE, Nelson CA, Knafl KA. Investigators' successful strategies for working with institutional review boards. *Research in nursing & health.* 2013;36(5):478-486.

292. Hickman SE, Cartwright JC, Nelson CA, Knafl K. Compassion and vigilance: Investigators' strategies to manage ethical concerns in palliative and end-of-life research. *Journal of palliative medicine.* 2012;15(8):880-889.

293. Williams MN, Grajales CAG, Kurkiewicz D. Assumptions of multiple regression: correcting two misconceptions. *Pract. Assess. Res. Eval.* 2013;18:1-14.

294. De Morgan S, Redman S, D'Este C, Rogers K. Knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women

diagnosed with ductal carcinoma in situ (DCIS). *Patient Education and Counseling.* 2011;84(1):62-68.

295. LeBlanc A, Kenny DA, O'Connor AM, Legare F. Decisional Conflict in Patients and Their Physicians: A Dyadic Approach to Shared Decision Making. *Medical Decision Making.* 2009;29(1):61-68.

296. Song L, Weaver MA, Chen RC, et al. Associations between patient-provider communication and socio-cultural factors in prostate cancer patients: A cross-sectional evaluation of racial differences. *Patient Education and Counseling.* 2014;97(3):339-346.

297. Legare F, Tremblay S, O'Connor AM, Graham ID, Wells GA, Jacobsen MJ. Factors associated with the difference in score between women's and doctors' decisional conflict about hormone therapy: a multilevel regression analysis. *Health Expect.* 2003;6(3):208-221.

298. Kaplan AL, Crespi CM, Saucedo JD, Connor SE, Litwin MS, Saigal CS. Decisional Conflict in Economically Disadvantaged Men With Newly Diagnosed Prostate Cancer. *Cancer.* 2014;120(17):2721-2727.

299. Song L, Hamilton JB, Moore AD. Patient-Healthcare Provider Communication: Perspectives of African American Cancer Patients. *Health Psychology.* 2012;31(5):539-547.

300. Hack TF, Degner LF, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Social Science & Medicine.* 1994;39(2):279-289.

301. Guadagnoli E, Ward P. Patient participation in decision-making. *Social Science & Medicine.* 1998;47(3):329-339.

302. O'Brien MA, Whelan TJ, Charles C, et al. Women's perceptions of their treatment decision-making about breast cancer treatment. *Patient education and counseling.* 2008;73(3):431-436.

303. Fallowfield LJ. Treatment decision-making in breast cancer: the patient–doctor relationship. *Breast Cancer Res Treat.* 2008;112(1):5-13.

304. Roter DL. Patient participation in the patient-provider interaction: the effects of patient question asking on the quality of interaction, satisfaction and compliance. *Health Education & Behavior.* 1977;5(4):281-315.

305. Ley P. Improving patients' understanding, recall, satisfaction and compliance. *Health psychology*: Springer; 1989:74-102.

306. Fallowfield LJ, Hall A, Maguire GP, Baum M. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *Bmj.* 1990;301(6752):575-580.

307. Kremer H, Ironson G, Schneiderman N, Hautzinger M. ``It's My Body'': Does Patient Involvement in Decision Making Reduce Decisional Conflict? *Medical Decision Making.* 2007;27(5):522-532.

308. O'Brien LA, Grisso JA, Maislin G, et al. Nursing home residents' preferences for life-sustaining treatments. *Jama.* 1995;274(22):1775-1779.

309. Garrido MM, Prigerson HG. The End-of-Life Experience: Modifiable Predictors of Caregivers' Bereavement Adjustment. *Cancer.* 2014;120(6):918-925.

310. Higgins PC, Prigerson HG. Caregiver Evaluation of the Quality of End-Of-Life Care (CEQUEL) Scale: The Caregiver's Perception of Patient Care Near Death. *Plos One.* 2013;8(6).

311. Akiyama A, Numata K, Mikami H. Importance of end-of-life support to minimize caregiver's regret during bereavement of the elderly for better subsequent adaptation to bereavement. *Archives of Gerontology and Geriatrics.* 2010;50(2):175-178.

312. Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? *Journal of palliative medicine.* 2005;8(6):1176-1185.

313. Barry LC, Kasl SV, Prigerson HG. Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *The American journal of geriatric psychiatry.* 2002;10(4):447-457.

314. Hebert RS, Schulz R, Copeland V, Arnold RM. What questions do family caregivers want to discuss with health care providers in order to prepare for the death of a loved one? An ethnographic study of caregivers of patients at end of life. *Journal of palliative medicine.* 2008;11(3):476-483.

315. Brazil K, Cupido C, Taniguchi A, Howard M, Akhtar-Danesh N, Frolic A. Assessing Family Members' Satisfaction with Information Sharing and Communication during Hospital Care at the End of Life. *Journal of Palliative Medicine.* 2013;16(1):82-86.

316. Tucker JS, Mueller JS. Spouses' social control of health behaviors: Use and effectiveness of specific strategies. *Personality and Social Psychology Bulletin.* 2000;26(9):1120-1130.

317. Corrao S, Santalucia P, Argano C, et al. Gender-differences in disease distribution and outcome in hospitalized elderly: Data from the REPOSI study. *European Journal of Internal Medicine.* 2014;25(7):617-623.

318. Russ AJ, Kaufman SR. Family perceptions of prognosis, silence, and the "suddenness" of death. *Culture Medicine and Psychiatry.* 2005;29(1):103-123.

319. Valdimarsdóttir U, Helgason ÁR, Fürst C-J, Adolfsson J, Steineck G. Awareness of husband's impending death from cancer and long-term anxiety in widowhood: a nationwide follow-up. *Palliative medicine.* 2004;18(5):432-443.

320. Lewis-Newby M, Curtis JR, Martin DP, Engelberg RA. Measuring Family Satisfaction with Care and Quality of Dying in the Intensive Care Unit: Does Patient Age Matter? *Journal of Palliative Medicine.* 2011;14(12):1284-1290.

321. Huang HL, Chiu TY, Lee LT, Yao CA, Chen CY, Hu WY. Family experience with difficult decisions in end-of-life care. *Psycho-Oncology.* 2012;21(7):785-791.

322. Azoulay E, Chevret S, Leleu G, et al. Half the families of intensive care unit patients experience inadequate communication with physicians. *Critical Care Medicine.* 2000;28(8):3044-3049.

323. Lynn J, Teno JM, Phillips RS, et al. Perceptions by family members of the dying experience of older and seriously ill patients. *Annals of Internal Medicine.* 1997;126(2):97-106.

324. Kaiser K, Rauscher GH, Jacobs EA, Strenski TA, Ferrans CE, Warnecke RB. The import of trust in regular providers to trust in cancer physicians among white, African American, and Hispanic breast cancer patients. *Journal of general internal medicine.* 2011;26(1):51-57.

325. Benjamins MR. Religious influences on trust in physicians and the health care system. *The International Journal of Psychiatry in Medicine.* 2006;36(1):69-83.

326. Street RL, Jr., Gordon H, Haidet P. Physicians' communication and perceptions of patients: Is it how they look, how they talk, or is it just the doctor? *Social Science & Medicine.* 2007;65(3):586-598.

327. Cooper-Patrick L, Gallo JJ, Gonzales JJ, et al. Race, gender, and partnership in the patient-physician relationship. *Jama.* 1999;282(6):583-589.

328. Manfredi C, Kaiser K, Matthews AK, Johnson TP. Are racial differences in patient–physician cancer communication and information explained by

background, predisposing, and enabling factors? *J Health Commun.* 2010;15(3):272-292.

329. Wray RJ, McClure S, Vijaykumar S, et al. Changing the conversation about prostate cancer among African Americans: results of formative research. *Ethnicity & health.* 2009;14(1):27-43.

330. Deep KS, Griffith CH, Wilson JF. Changes in internal medicine residents' attitudes about resuscitation after cardiac arrest over a decade. *J. Crit. Care.* 2009;24(1):141-144.

331. Conner N. End-of-life informal caregiving and decision-making experiences among blacks. Paper presented at: Annual Meeting of the Southern Nursing Research Society2009.

332. Zhang AY, Siminoff LA. The role of the family in treatment decision making by patients with cancer. Paper presented at: Oncology nursing forum2003.

333. Garrett JM, Harris RP, Norburn JK, Patrick DL, Danis M. Life-sustaining treatments during terminal illness. *Journal of General Internal Medicine.* 1993;8(7):361-368.

334. Goodlin SJ, Zhong Z, Lynn J, et al. Factors associated with use of cardiopulmonary resuscitation in seriously ill hospitalized adults. *Jama.* 1999;282(24):2333-2339.

335. Hopp FP, Duffy SA. Racial variations in end-of-life care. *Journal of the American Geriatrics Society.* 2000.

336. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Annals of Internal Medicine.* 2000;132(10):825-832.

337. Crawley L, Payne R, Bolden J, Payne T, Washington P. Palliative and end-of-life care in the African American community. *Jama.* 2000;284(19):2518-2521.

338. Koenig BA, Gates-Williams J. Understanding cultural difference in caring for dying patients. *Western Journal of Medicine.* 1995;163(3):244.

339. Bullock K. The influence of culture on end-of-life decision making. *Journal of social work in end-of-life & palliative care.* 2011;7(1):83-98.

340. Borrego M, Douglas EP, Amelink CT. Quantitative, qualitative, and mixed research methods in engineering education. *Journal of Engineering Education.* 2009;98(1):53-66.

341. Addington-Hall J, McPherson C. After-death interviews with surrogates/bereaved family members: Some issues of validity. *Journal of Pain and Symptom Management.* 2001;22(3):784-790.

342. McPherson C, Addington-Hall J. Judging the quality of care at the end of life: can proxies provide reliable information? *Social science & medicine.* 2003;56(1):95-109.

343. Christakis NA. The ellipsis of prognosis in modern medical thought. *Social science & medicine.* 1997;44(3):301-315.

344. Del Vecchio Good M-J, Good BJ, Schaffer C, Lind SE. American oncology and the discourse on hope. *Culture, medicine and psychiatry.* 1990;14(1):59-79.

345. Katz J. *The silent world of doctor and patient.* JHU Press; 2002.

346. Elias N. The Loneliness of the Dying Basil Blackwell. Oxford; 1985.

347. Connors AF, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Jama.* 1995;274(20):1591-1598.

348. Earle CC, Ayanian JZ. Looking back from death: the value of retrospective studies of end-of-life care. *Journal of Clinical Oncology.* 2006;24(6):838-840.

CURRICULUM VITAE

Esther Renee Smith-Howell

EDUCATION:

Degree	Institution	Year	Preparation
BHS	University of Florida Science	2006	Health
BSN	Indiana University	2009	Nursing
PhD	Indiana University	2015	Nursing
Post-Doctorate	University of Pennsylvania	Begins 2015	Nursing

ACADEMIC APPOINTMENTS:

Institution	Title	Dates
Indiana University School of Nursing Indianapolis, Indiana	Research Assistant	2008-2010
Indiana University School of Nursing Indianapolis, Indiana	Research Assistant	2010
Indiana University School of Nursing Indianapolis, Indiana	Teaching Assistant	2012
Indiana University School of Nursing Indianapolis, Indiana	Teaching Assistant	2014

CLINICAL APPOINTMENTS:

Institution	Title	Dates
Community Hospital East Intensive Care Unit Indianapolis, Indiana	Student Nurse Extern	2008-2009

LICENSURE AND CERTIFICATIONS:

Type	State
Registered Nurse	Indiana

HONORS:

Name	Granted By	Dates
PhD Student Poster - First Place	Midwest Nursing Research Society	2010

PhD Student Poster - First Place	Indiana University Simon Cancer Center	2010
Outstanding Poster Award	Richard L. Roudebush Veteran Affairs Medical Center	2010
Elite 50 Award	Indiana University-Purdue University Indianapolis/Graduate and Professional Student Government at IUPUI	2015
Premier 10 Award	Indiana University-Purdue University Indianapolis/Graduate and Professional Student Government at IUPUI	2015
Best in the Indiana University School of Nursing	Indiana University-Purdue University Indianapolis/Graduate and Professional Student Government at IUPUI	2015
Indiana University School of Nursing Recognition Program Commencement Speaker	Indiana University School of Nursing	2015

AWARDS:

Grants

<u>Name</u>	<u>Granted By</u>	<u>Amount</u>	<u>Dates</u>
Research Incentive Fund Fellowship	Indiana University School of Nursing	$10,000	2010
Research Incentive Fund Fellowship	Indiana University School of Nursing	$10,000	2011
Ruth L. Kirschstein National Research Service Award For Individual Predoctoral Fellowships to Promote Diversity in Health-Related Research (1F31NR013613-01)	National Institute of Nursing Research/ Indiana University School of Nursing	$110,952	2012-2015
Research Incentive Fund Fellowship	Indiana University School of Nursing	$10,000	2012
Research Incentive Fund Fellowship	Indiana University School of Nursing	$10,000	2013

Name	Awarded By	Amount	Dates
Research Incentive Fund Fellowship	Indiana University School of Nursing	$10,000	2014

Fellowships

Name	Awarded By	Amount	Dates
Pre-Doctoral Fellowship	Indiana University School of Nursing/ The Fairbanks Foundation	$20,000	2009
Behavioral Cooperative Oncology Group Pre-Doctoral Fellowship	Mary Margaret Walther Program for Cancer Care Research	$10,386	2010
Training in Health Behavior Research Fellowship (T32NR007066)	National Institute of Nursing Research/ Indiana University School of Nursing	$21,180	2010
Behavioral Cooperative Oncology Group Pre-Doctoral Fellowship	Mary Margaret Walther Program for Cancer Care Research	$21,180	2011
Dean's Distinguished Postdoctoral Fellowship	University of Pennsylvania	$150,000	2015-2018

Name	Awarded By	Amount	Dates
Irene and Nathaniel Aycock Scholarship	Sally Tate	$1,666	2010
Irene and Nathaniel Aycock Scholarship	Sally Tate	$1,666	2010
Florence Nightingale Scholarship	Indiana University School of Nursing	$1,800	2010
Spotlight on Nursing Scholarship	Spotlight on Nursing	$5,000	2011
Spotlight on Nursing Scholarship	Spotlight on Nursing	$5,000	2012
PhD Leadership Fellowship Award	Indiana University School of Nursing	$1,000	2012
Minority Nurse Faculty Scholars Program	Johnson & Johnson/ American Association of Colleges of Nursing	$18,000	2012

Nursing 2000, Graduate Colleges of Nursing	Indiana University School of Nursing	$1,000	2012
Irene and Nathaniel Aycock Scholarship	Sally Tate	$2,500	2012
Minority Nurse Faculty Scholars Program	Johnson & Johnson/ American Association of	$18,000	2013
Spotlight on Nursing Scholarship	Spotlight on Nursing	$2,500	2014

SERVICE:

University Service

Organization	Role	Dates
Indiana University School of Nursing Undergraduate President's Council	Member	2008-2009
Indiana University School of Nursing Career Connections For Underrepresented Undergraduate Students	Attendee	2008 - Present
Behavioral Cooperative Oncology Group Pre-Doctoral Fellowship	Fellow Colloquium Icebreaker Co-Leader	2011
Indiana University School of Nursing Bridge Project	Attendee	2012
Indiana University School of Nursing Search and Screen Committee	Member	2012
National Institutes of Health Regional Seminar on Program Funding and Grants Administration	Volunteer	2012
Indiana University School of Nursing	Summer Intensive Student Panelist	2012

St. Vincent's Hospital/ Indiana University School Of Nursing	Poverty Experience Simulation Volunteer	2012
Behavioral Cooperative Oncology Group Pre-Doctoral Fellowship	Fellow Colloquium Icebreaker Co-Leader	2012
St. Vincent's Hospital/ Indiana University School Of Nursing	Poverty Experience Simulation Volunteer	2013
Indiana University School of Nursing	Honor Student Colloquium Speaker	2013

Community Service

Organization	**Role**	**Dates**
Shands Hospital	Volunteer	2004-2005
National Association For Female Executives	Feed the Veterans Volunteer	2008
Catch the Stars Foundation, Incorporated	Catch on to Fitness Volunteer	2009
Eastern Star Church	Christmas Under the Stars Participant	2009
American Cancer Society	Associate Council	2010 - 2011 Ambassador
	Race for the Cure Volunteer	2010
Chi Eta Phi Sorority, Incorporated	The Julian Center Women's Heart Health Education Seminar Co-Leader	2010
	Historian's Assistant	2011-Present
Spotlight on Nursing	The 10th Annual Spotlight On Nursing Run/Walk Volunteer	2011

Girls, Inc. of Greater Indianapolis	Redefining Beauty Program Co-Facilitator	2012
Big Brothers Big Sisters of Central Indiana	Big Sister	2012-2013
Hoosier Veterans Assistance Foundation/ American Legion University Veterans Post 360 and Veterans	Christmas Dinner Volunteer	2012
Spotlight on Nursing	The 11th Annual Spotlight On Nursing Run/Walk Volunteer	2012
Kids Against Hunger	Volunteer	2013
National Association of Female Executives/ Women in Networking/ Richard Roudebush Veterans Affairs Medical Center	"Sharing Day" Volunteer	2013
Spotlight on Nursing Run/Walk Volunteer	The 10th Annual Spotlight On Nursing	2014

PRESENTATIONS:

Peer-Reviewed Poster Presentations

1. **Smith-Howell, E.R**., Krier, C., Rawl, S. (2009). "Colorectal Cancer Knowledge Among African Americans: Does Gender and Health Literacy Matter". Poster presented at the Indiana University Simon Cancer Center, Cancer Research Day, Indianapolis, IN; April 2009.

2. **Smith-Howell, E.R.**, Rawl, S., Champion, V., Skinner, C., Springston, J., Krier, C., Russell, K., Perkins, S., Broderick, R., Lloyd, F., Willis, D., Imperiale, T., Myers, L. "Exploring the Role of Cancer Fatalism as a Barrier to Colorectal Cancer Screening." Poster presented at 34th Midwest Nursing Research Society, April 8-11, 2010, Kansas City, MO. *Received 1st Place PhD Student Poster.*

3. **Smith-Howell, E.R.**, Rawl, S., Champion, V., Skinner, C., Springston, J., Krier, C., Russell, K., Perkins, S., Broderick, R., Lloyd, F., Willis, D., Imperiale, T., Myers, L. (2010). "Exploring the Role of Cancer Fatalism as a Barrier to Colorectal Cancer Screening". Poster presented at the Richard L. Roudebush Veterans Affairs Medical Center 2nd Annual Research Symposium, Indianapolis, Indiana; April 2010. *Received Outstanding Poster Award.*

4. **Smith-Howell, E.R**., Rawl, S.M., Champion, V.L., Skinner, C.S., Springston, J., Krier, C., Russell, K.M., Perkins, S., Rhyant, B., Lloyd, F., Willis, D., Imperiale, T., & Myers, L.J. "Exploring the Role of Cancer Fatalism as a Barrier to Colorectal Screening". Poster presented at Cancer Research Day, IU Simon Cancer Center, Indianapolis, IN; May 6, 2010. ***Received 1st Place Graduate Student Poster Award.***

5. **Smith-Howell, E.R.** & Hickman, S. E. (2012). "End-of-Life Decision-Making among African Americans with Advanced Cancer". Poster presented at the Oncology Nursing Society Connections: Advancing Care Through Science Conference, Phoenix, AZ; November 2012.

6. **Smith-Howell, E.R**. & Hickman, S. E. (2012). "End-of-Life Decision-Making among African Americans with Advanced Cancer". Poster presented at the RESPECT Center conference -Translating Research into Best Practice: Improving Palliative and End-of-life Care, Indianapolis, IN; March 2013.

Peer-Reviewed Oral Presentations

1. **Smith-Howell, E.R.**, Hickman, S. E., Rawl, S. M., Habermann, B., Perkins, S. (2013). "Effective Recruitment Strategies of Bereaved African American Family Members in an End-of-Life Pilot Study". Oral presentation at the 2013 Annual MNRS Research Conference, Chicago, IL; March 2013.

Invited Presentations

1. **Smith-Howell, E.R.** & Hines, D.D. (2014) "Debunking the Myths of the Dissertation Proposal Defense". Webinar presentation – American Association of Colleges of Nursing Graduate Nursing Student Academy, Washington, D.C.; November 2014.

Invited Speaker
1. Conference Panelist - National Invitational Forum for Diversity, University of Pennsylvania; March 2014

PUBLICATIONS:

Peer-Reviewed Manuscripts

1. Rawl, S.M., Skinner, C.S., Perkins, S.M., Springston, J., Wang, H.L., Russell, K.M., Tong, Y., Gebregziabher, N., Krier, C., **Smith-Howell, E.R.**, Brady-Watts, T., Myers, L.J., Ballard, D., Rhyant, B., Willis, D.R., Imperiale, T.F., Champion, V.L. (2011). Computer-tailored Intervention Improves Colon Cancer Screening Knowledge and Health Beliefs of African Americans. Health Education Research, 27 (5) 868-885. PMID: 22926008.

2. Hickman, S.E., Nelson, C.A., Smith-Howell, E.R., Hammes, B.J. (2014). Use of the Physician Orders for Life-Sustaining Treatment (POLST) Program for Patients Being Discharged from the Hospital to the Nursing Facility. Journal of Palliative Medicine. J Palliative Medicine, 17 (2):256. PMC3887400.

Newsletters

1. **Smith-Howell, E.R.**, Rawl, S.M., Krier, C., Champion, V.L., Russell, K., Perkins, S., Tong, Y., Gebregziabher, N., Rhyant, B., Willis, D., Imperiale, T., Myers, L J., Skinner, C.S., Springston, J. (2010). Gender and Health Literacy Influence Colorectal Cancer Screening Knowledge among African-Americans. The Indiana Cancer Consortium Cancer Connection, 8 (1): 3.

2. **Smith-Howell, E.R.** (2010). Disparities in Cancer Outcomes: The Role of Race and Ethnicity. The Indiana Cancer Consortium Cancer Connection, 8 (4): 9-11.

Abstracts

1. **Smith-Howell, E.R.**, Rawl, S., Champion, V., Skinner, C., Springston, J., Krier, C., Russell, K., Perkins, S., Broderick, R., Lloyd, F., Willis, D., Imperiale, T., Myers, L. (2010). "Exploring the Role of Cancer Fatalism as a Barrier to Colorectal Cancer Screening". *Award-winning abstract.* Western Journal of Nursing Research, 33 (1) 140-141.

2. **Smith-Howell, E.R.** & Hickman, S. E. (2012). "End-of-Life Decision-Making among African Americans with Advanced Cancer". Oncology Nursing Forum, 39 (6) E543-E544.

Manuscripts in Progress:

1. **Smith-Howell, E.R.**, Hickman, S.E., Meghani, S.H., Perkins, S.M., Rawl, S.M. (2015). End-of-life Decision-Making and Communication of Bereaved Family Members of African Americans with Serious Illness.

2. **Smith-Howell, E.R.** & Hickman, S.E. (2014). The Importance of Religion in African American End-of-Life Decision-Making.

PROFESSIONAL ORGANIZATIONS:

Name	Dates
Indiana Alumni Association	2009 – Present
Midwest Nursing Research Society	2009 – Present
Chi Eta Phi Sorority, Incorporated	2010 – Present
Hospice and Palliative Nurses Association	2010 – Present
Oncology Nursing Society	2010 – Present
Sigma Theta Tau International Honor Society of Nursing	2010 – Present
National Black Nurses Association	2014 - Present

American Academy of Hospice and Palliative Medicine	2014 - Present
Gerontological Society of America	2015

CONTINUING EDUCATION:

Conferences Attended	Dates
Midwest Nursing Research Society Annual Conference	2009
Behavioral Cooperative Oncology Group Annual Conference	2009
Midwest Nursing Research Society Annual Conference	2010
Behavioral Cooperative Oncology Group Annual Conference	2010
Institute on Teaching and Mentoring	2011
Midwest Nursing Research Society Annual Conference	2011
The Science of Compassion: Future Directions in End-of-Life and Palliative Care	2011
Behavioral Cooperative Oncology Group Annual Conference	2011
Behavioral Cooperative Oncology Group Summer Retreat	2012
Institute on Teaching and Mentoring	2012
Oncology Nursing Society Connections: Advancing Nursing through Science	2012
American Association of Colleges of Nursing Faculty Development Conference	2013
RESPECT Center conference -Translating Research into Best Practice: Improving Palliative and End-of-life Care	2013
Midwest Nursing Research Society Annual Conference	2013
Sigma Theta Tau International 24th International Nursing Research Congress	2013
Behavioral Cooperative Oncology Group Annual Conference	2013
RESPECT Center conference -Translating Research into Best Practice: Improving Palliative and End-of-life Care	2014
National Invitational Forum for Diversity – University of Pennsylvania	2014
100th Anniversary Distinguished Lectureship Conference- Indiana University	2014
American Society of Clinical Oncology - Palliative Care in Oncology Symposium	2014
Behavioral Cooperative Oncology Group Annual Conference	2014
Annual Assembly of the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association	2015