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Leadership and End-of-Life Planning Among Elderly Patients With End-Stage Renal Disease

Elizabeth R. Armstrong-Fears
Walden University

Walden University

College of Health Sciences

This is to certify that the doctoral study by

Elizabeth R. Armstrong-Fears

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Dr. Suzanne Richins, Committee Chairperson, Health Sciences Faculty
Dr. Rabeh Hijazi, Committee Member, Health Sciences Faculty
Dr. Ronald Hudak, University Reviewer, Health Sciences Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

Walden University
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Abstract

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MA/MS, University of Phoenix, 2015

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Doctoral Study Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Healthcare Administration

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Abstract

More than 8-million people in the United States possess no kidney function. The purpose of this quantitative casual-comparative research study is to examine the relationship between ethnicity status of African American and European American patients suffering from end-stage renal disease, and advanced care planning and end-of-life decision-making among patients who are 55 years of age and older. The health belief model is the selected explanatory framework used to examine (a) whether ethnicity status is a significant predictor of whether decedents had written end-of-life care instructions, (b) whether ethnicity status is a significant predictor of whether treatment decisions were made, and (c) whether ethnicity status is a predictor of whether patients 55 years of age and older were able to participate in these decisions during the final days of life. The quantitative causal-comparative research design utilized a secondary data set with 4,172 European Americans, of whom 1,010 (24.2%) died from kidney disease, and 1,013 African American in the sample with 289 (28.6%) who died from kidney disease. The logistic regression resulted in the rejection of the null hypothesis for each of the three research questions. The study results may be used by executive leaders to understand factors of patient safety, value-based care, medical technology, health care resources for family, and caregivers that ultimately increase the quality of life of the patient and care needs at the end of life.

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Dedication

This doctoral research study is dedicated to Amelia C. Armstrong, my mother, who passed away from end-stage renal disease in 2015. My mother is the one who inspired me to write about the importance of healthcare leaders, physicians, staff, and family honoring and respecting the wishes of the terminally ill patient. Thank you, mom, you are greatly missed.

Acknowledgments

I want to acknowledge my husband, Carl. E. Fears for always being supportive. Additionally, I want to thank my Got Muscle Health Club family, Kaiser Permanente family, Dr. Shelley Grone, Dr. Hoki Min. My chair Dr. Richins, Dr. Willis, Walden committee, and Walden cohorts, who have helped me through this doctoral program. I thank each of you.

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Introduction

Aging patients who are 55-years-of-age or older, who have the ethnicity status operationalized as African American, and European American diagnosed as terminally ill, and who are at the end of life are highly vulnerable and need support during this phase. There is evidence that members of the African American population feel the end-of-life process is stressful and many in this population are not willing to accept death from the advanced illness, but instead choose to seek life support and nutritional support, compared to and European Americans (Death, 2019). African Americans are less likely than and European Americans to participate in the end-of-life planning process (Rollins, 2018).

The ultimate goal of end-of-life planning is to support the patient and provide the terminally ill patient a better quality of life by designating someone to function as the patient’s voice at the end-of-life process. Research provides insight into the underuse of hospice services in the older African American population, compared to the European Americans, attributed to spiritual beliefs and a lack of trust in the healthcare system (Fraham et al., 2011). Previous research reveals reasons African American patients newly diagnosed with an advanced illness such as end-stage renal disease and their families struggle with making health care decisions prior to the time-of-death (Washington, 2016). The researcher has found no evidence that European American underuse hospice care more than African Americans (Ladin, 2018).

Research on the topic of leadership and end-of-life planning among elderly African American, and European American patients with end-stage renal disease requires further research to improve communication between the patient with end-stage renal disease, the physicians, family, and hemodialysis staff. The improved communication among these groups could improve participation in advance care planning and can be used as a guide for quality and preferences at the end of life (Eneanya, 2015). Essentially, improving communication and quality of care is the social change that will come from this research. Furthermore, findings from this research may bring social change to executive leaders through factors of patient safety, value-based care, medical technology, health care resources for family, and caregivers that ultimately increases the quality of life of the patient and care needs in the end-of-life period (Council, 2015).

o improve quality in health care, there is a need to focus on value for patient outcomes during the end-of-life period. Efforts to respect the patient’s wishes will drive improvements for care and build quality performance for health care administrators and executive leaders in the United States (Illness, 2017). Additionally, some families are not willing to accept death or discuss the health care decisions of the terminally ill patient or family member (Grant, 2017). Advanced illness findings are based on the relationships between end-of-life, family engagement, and overall quality of care (Smith-Howell, 2016). The goal of hospice utilization and end-of-life process is to support the patient, giving the terminally ill patient a better quality of life and designating someone as the patient’s voice during the end-of-life process (Washington, 2016).

Problem Statement

For patients who are 55-years-of-age, and who have the ethnicity status of African American, and European American, research provides insight on the underuse of hospice services in the older African American population that is attributed to spiritual beliefs and a lack of trust in the healthcare system (Eneanya, 2015). Furthermore, research supports that there are racial/ethnic differences in end-of-life treatments and how minority groups look for sustaining life-long treatments as opposed to utilizing hospice treatments (Smith-Howell, 2016). Education plays a significant role in how different cultures deal with family members who are terminally ill to participate in hospice utilization and end-of-life planning process (Eneanya, 2015).

Researchers have examined the African American, European American, and Hispanic patients with end-stage renal disease, looking at health care decision-making for both ethnic/racial minority populations and nonminority populations analyzing the roles played by family members (Harding, 2017). In a qualitative descriptive study comparing African American patients to Hispanic and European Americans on end-of-life planning and shared decision-making of treatment options and replacement therapy (e.g., hemodialysis, peritoneal dialysis), Ladin (2018) found that only 13% of patients had discussions with their physician about end-of-life planning out of the three ethnic groups.

The intent was to find differences between patients and families in the African American group as opposed to other racial/ethnicity groups with end-stage renal disease. An empirical study using interviews and focus groups found there was a greater need for improved engagement for both ethnic/racial minorities and non-minorities (Sheu, 2012).

End-of-life family planning assists with financial pressures and provides a caregiver or surrogates to make the decisions based upon what has been written by the patient. Essentially, the end-of-life is about the patient and quality of care for defining treatment options to assist with managing the process of dying (Boucher, 2016).

The end-of-life process presents several areas of concerns and challenges that need to be explored to examine experiences and communication, and to understand the process of end-of-life planning for patients with end-stage renal disease. Some of the challenges and concerns are to understand why there are less engagement for improving engagement in the populations that appear to have less engagement with the end-of-life planning process in African American, Hispanic, and European American populations (Novelli, 2015).

Healthcare leaders are concerned about the lack of end-of-life planning to guide patient-centered care in aging African American, Hispanic, and European American patients who are 55-years-of-age and older and suffering from end-stage renal failure (Wachterman et al., 2017). Furthermore, the end-of-life process is a sensitive topic that takes people through a range of emotions. However, death requires planning for the event of someone’s passing. For the terminally ill and surrounding family members, the events center on healthcare executives, creating clear guidelines, and documented processes for understanding the background and supporting the patient with preparation for end-of-life care.

In some family structures, there are cultural barriers that make the end-of-life period challenging for both the patient and the surviving family members. In health care, end-of-life planning entails appointing someone close to the patient to act as a voice if the patient is unable to speak (Novelli, 2015). However, to improve the quality of care, leaders need to focus on patient goals, preferences, and value for patient outcomes during the end-of-life phase to meet the requirements for patient-centered care (Death, 2019).

According to the Joint Commission (VandeRiet, 2019) healthcare leaders are required to understand and know the principles of care for embracing quality principles of treatments for the patient exactly as written at the end of life. Essentially, healthcare leaders are required to have ethical relationships for positive outcomes based on the quality of care, patient safety, and organizational cost (VandeRiet, 2019). Furthermore, the Joint Commission requires healthcare leaders to honor and respect patient rights for culturally appropriate care that includes being informed of treatment having the right to refuse pain medications and being listened to with courtesy and respect (Joint, 2012). Advance care directives are a general document that includes written instructions from the patient that informs healthcare leaders of their wishes during the end-of-life planning process.

Previous studies identified low rates of advance care directives contributing to the high cost of health care treatments at the end of life, especially among older adults who are African American with an advanced, terminal illness compared to the other two racial and ethnic groups under study, which are European American and Hispanic (Crews, 2018). Furthermore, in this population, African Americans are less likely to participate with end-of-life planning or to have identified a family health care decision-maker on file upon hospice utilization or readmission to the hospital (Kelley, 2018).

Studies also support that African Americans have less family involvement prior to death (Washington, 2016). Efforts to respect the patient’s wishes may drive improvements for the high quality of care, person-and-family centered care, build quality performance as required for health care administrators and executive leaders in the United States (Illness, 2017). According to the United States Renal Data system, there are more than 661,000 Americans suffering from end-stage renal disease, and African Americans are considered 3.7 times more likely to be diagnosed, when compared to European American (Harding, 2017).

However, Hispanic Americans make up 14% of the 661,000 population with end-stage renal disease (Death, 2019). End-stage renal disease is one of the fastest-growing illnesses among certain populations (e.g., African Americans and Hispanics; Centers for Disease Control and Prevention, 2015). One in seven people is estimated to have kidney disease in the United States (Death, 2019). The specific problem is that more than 8 million people in the United States possess no kidney function (Centers for Disease Control and Prevention, 2015).

This study examined the relationship between ethnicity status and advance care planning and end-of-life decision-making among those who are 55 years of age and older since few of these patients among this age population have created an end-of-life plan (Death, 2019). Specific variables used in this study include ethnicity status and end-of-life care instructions that will assist in addressing this ethnicity status gap. The results may help healthcare leaders implement practices and policies for culturally responsive care for elderly patients with end-stage renal disease. A plan of the next steps will give the family, health care administrators, and executive leadership time to prepare advocacy plans for the patient. According to previous studies, the end-of-life experience should honor the patient's wishes (Grant, 2017).

Purpose of the Study

The purpose of this quantitative casual-comparative research study was to examine the relationship between ethnicity status, operationalized as African American, Hispanic, and European American, and advance care planning and end-of-life decision-making among those who are 55 years of age and older. Ethnicity is defined as African Americans, Hispanics, and European Americans (Crews, 2018).

Advance care planning and end-of-life decision-making is defined as whether the decedents had written end-of-life care instructions (yes or no), whether treatment decisions need to be made in the final days of life (yes or no), and whether the elderly patients were able to participate in these decisions (e.g., medical treatment, spiritual wishes, resuscitate, nutrition, and family involvement). Healthcare leaders need more information about end-of-life planning in order to meet the needs in the patient delivery of care. In this study, I used multiple logistic regression to evaluate the research questions and intervening variables of communication between patient and doctor, and health beliefs of patients who may not want to participate.

Research Questions

Research Question 1: To what extent is ethnicity status, operationalized as African American, Hispanic, and European American, a significant predictor of whether the decedents had written end-of-life care instructions on file among patients who are 55 years of age and older who have end-stage renal disease?

$H1_0$: Ethnicity status, operationalized as African American, Hispanic, and European American, is not a significant predictor of whether the decedents had written end-of-life care instructions.

$H1_a$: Ethnicity status, operationalized as African American, Hispanic, and European American, is a significant predictor of whether the decedents had written end-of-life care instructions.

Research Question 2: To what extent is ethnicity status, operationalized as African American, Hispanic, and European American, a significant predictor of whether documented treatment decisions in the final days of life, defined as whether decisions needed to be made in the final days of life among those who are 55 years of age and older who have end-stage renal disease?

$H2_0$: Ethnicity status, operationalized as African American, Hispanic, and European American, is not a significant predictor whether documented treatment decisions needed to be made in the final days of life among those who are 55 years of age and older.

$H2_a$: Ethnicity status, operationalized as African American, Hispanic, and European American, is a significant predictor of whether treatment decisions need to be made in the final days of life among those who are 55 years of age and older.

Research Question 3: To what extent is ethnicity status, operationalized as African American, Hispanic, and European American, a significant predictor of whether the elderly patients were able to participate in treatment decisions among those who are 55 years of age and older who have end-stage renal disease?

H3_0: Ethnicity status, operationalized as African American, Hispanic, and European American, is not a significant predictor of a significant predictor of whether the elderly patients were able to participate in these decisions among those who are 55 years of age and older.

H3_a: Ethnicity status, operationalized as African American, Hispanic, and European American, is a significant predictor of a significant predictor of whether the elderly patients were able to participate in these decisions among those who are 55 years of age and older.

Theoretical Foundation for the Study

The health belief model was the selected framework for this doctoral study to evaluate personal beliefs, communication, health behaviors, knowledge, personal health communication, of the independent variable of ethnicity status, operationalized as African American, European American, and Hispanic American (Rollins, 2018). Additionally, this research study provided information for evaluating the dependent variables, and evaluating whether the decedents had documented written end-of-life care instructions, whether treatment decisions need to be made in the final days of life, and whether the elderly patients were able to participate in these decisions during the end-of-life period. The health belief model is used to understand better communication, processes, and other questions that may not have answers (Jones, 2016).

For this study, I used the health belief model as an explanatory framework to explore ethnicity status and behaviors that cause less participation in end-of-life care instructions. Additionally, the health belief model was used as a guide for constructing undefined behaviors that may assist with explaining variables in this research study by evaluating the ethnicity status gap to help implement practices and policies for culturally responsive care for elderly patients with end-stage renal disease.

The health belief model (HBM) is an explanatory communication research tool that may assist with the mediation of understanding the relationship of why most people have not thought or have had the end-of-life conversation (Becker, 1974: Champion & Skinner, 2008; Rosenstock, 1974). Furthermore, HBM may assist in model construction for healthcare leadership (e.g., physicians, managers, executives) to take action on writing policies on behaviors that may influence the behavior of not wanting to engage or participate in hospice utilization, and the end-of-life planning process. HBM explanatory framework may support and assist with assessing the behaviors influencing whether the decedents had written end-of-life care instructions or whether treatment decisions need to be made in the final days of life or whether the elderly patients were able to participate in these decisions (e.g., medical treatment, spiritual wishes, resuscitate, nutrition, and family involvement.).

The health belief model was used to identify variables for performing statistical analysis of barriers between health care decision-making with intent to evaluate to determine the health beliefs that prevent African Americans from engaging in hospice utilization during the end-of-life period. Quantitative research is consistent and may show documented measures for adults in the United States with end-stage renal disease and cancer diagnosis. Quantitative research also has internal documented measures of rates of advance care directives being on the low side, and rates of health care treatments being on a high at the end of life, especially among older adults who are African American (Hayes, 2012). Additionally, quantitative data has information on quality improvements, hospital readmissions, and hospice utilization that have been collected and documented for the cross-comparison of this study. The table below refers to research questions and variables used in this research study, to assist with aligning the independent variables, and dependent variables for those who 55 years of age and older.

Table 1

The Health Belief Model

	The health belief model variables	
Research questions	IVs	DV
To what extent is ethnicity status a significant predictor of whether the decedents had written end-of-life care instructions for those who are 55 years of age and older?	African American, Hispanic, European American	Whether the decedents had written end-of-life care instructions
To what extent is ethnicity status a significant predictor of whether treatment decisions were made in the final days of life among those who are 55 years of age and older?	African American, Hispanic, European American	Whether treatment decisions need to be made in the final days of life
To what extent is ethnicity status a significant predictor of whether the elderly patients were able to participate in these decisions for those who are 55 years of age and older?	African American, Hispanic, European American	Whether the elderly patients were able to participate in these decisions

Note. IV = Independent variable; DV = Dependent variable.

Nature of Study

In this doctoral research study, I used the quantitative causal-comparative research design to find relationships between the dependent and independent variables for whether the decedents had written end-of-life care instructions or whether treatment decisions need to be made in the final days of life or whether the elderly patients were able to participate in these decisions (e.g., medical treatment, spiritual wishes, resuscitate, nutrition, and family involvement.).

The quantitative research design was chosen for three reasons. First, quantitative research is used to collect numerical data to assess whether there are statistically significant relationships or differences between variables (Creswell, 2018; Hair et al., 2018; Leedy & Omrod, 2018). The purpose of this study was to examine whether ethnicity status predicts advance care planning and end-of-life decision-making among those who are 55 years of age and older. Since ethnicity is coded as a numeric variable and advance care planning and end-of-life decision-making are also numeric variables, the quantitative methodology is appropriate for this study. Second, the quantitative study uses a relatively large sample size, which allows for the projectability of results to the target population (Creswell, 2018; Hair et al., 2018; Leedy & Omrod, 2018). Third, the qualitative methodology would have been inappropriate for this study because it cannot determine statistically significant relationships between variables, and it answers "how" and "why" questions, while the quantitative methodology answers "what" questions. I conducted a linear regression to determine if there is a predictive relationship between variables of interest as they exist in a defined population at a single point in time or over a short period of time (e.g., calendar year) (Creswell, 2018; Hair et al., 2018; Leedy & Omrod, 2018).

In the current study, I examined whether ethnicity status, operationalized as African American, Hispanic, and European American is a significant predictor of whether the decedents had written end-of-life care instructions for those who are 55 years of age and older. Additionally, I examined a numeric variable: end-of-life planning status predicts another numeric variable, advance care planning, and end-of-life decision-making among those who are 55 years of age and older.

Therefore, casual-comparative design was appropriate for this study. The experimental and quasi-experimental designs were not appropriate for this study as there was no pre and posttest or control group. Finally, this design was appropriate because other studies in this field have used this design (Grant, 2017; Illness, 2017; Wachterman et al., 2017; Washington, 2016).

Literature Search Strategy

The Walden University Library of databases were used for finding peer-reviewed articles and journals for this research study. The databases I used were ProQuest Health, Medline, American Journal, American Nephrology Nurses Association, American Journal of Nephrology, Supportive Care for The Renal Patient, Journal of Health Management, Journal of Health and Organization Management, Journal of Healthcare Policy, Omega Journal of Death and Dying, Journal of Pain and Symptom Management, BMC Health Service and Research, Frontier Journal of Health Services Management, and Department of Health. The terms and keywords used included *leadership, end-of-life* *planning, end-stage renal disease, elderly patients with advanced illness, chronic kidney disease, hemodialysis, advanced care planning,* and *written instructions,* and I obtained results from each of the databases used to research this study. The search was limited to peer-reviewed, scholarly journals and articles published between 2013 and 2019.

Bansal (2018) provided information on patients with end-stage renal disease who are near the end-of-life, and challenged with not having a healthcare decision-maker on file, that ultimately challenged the treating nephrologist with the best patient-centered care. Barnett (2016) focused on the patient who is critically ill with advanced illness and palliative care is given for quality of treatment. Additionally, this study addressed advanced illnesses, components, and experiences in palliative care for decision-making and consistency of best treatment during the end-of-life period. Chen (2018) addressed cost, end-of-life, and hospice incentives for the best care. Furthermore, this article focuses on how the end-of-life process can drive the cost of medical care.

Grant (2017) gave insight into cultural disparities and gaps for patients who are diagnosed with an advanced illness. This study also centers on end-of-life and the approach that families, caregivers, and healthcare professionals should engage in for better patient-centered care during the end-of-life process. Illness et al. (2017) addressed quality and improvements related to care and support to patients with an advanced illness. Additionally, the article is about the values of care, family engagement, and the goals for honoring the patient’s wishes at the end-of-life for the dignity of the patient.

Wachterman et al. (2017) provided information on patients with advanced illnesses who are older and dying. This article regarded the older Americans with end-stage renal disease and introduced the study of the health and retirement data collection for best understanding the knowledge of the patient after death.

Literature Review

Ladin (2018) highlighted family misunderstandings, terminology for interpreting details of diagnoses, communication, and decision-making for the next of kin is a challenge that ultimately leads to barriers of communication in older adults receiving inadequate information during the end-of-life discussions. The participants for this study were recruited to take part in interviews about health literacy, end-of-life planning, and goals about personal health care. Additionally, the researchers shared that 31 elderly dialysis patients participated, and the results from this study determined that 13% of patients had discussions on end-of-life with their physicians. Other key findings of this study were communication, lack of meaningful conversations for assisting with future care at the end of life.

Ephraim (2012) conducted a mixed-method study discussed African Americans with end-stage renal disease or an African American who has been diagnosed with a terminal illness (e.g., cancer, HIV, diabetes, etc.) suggesting that African Americans have less engagement than other racial or ethnic groups. Furthermore, additional research supports that European Americans account for the (81.5%) in the United States opposed to African Americans (8.6%), and Hispanics (6.9%) with underline use of advance care directives and engagement (Crews, 2018). Additionally, the study gave insight into the protocol of open access for the best care and focuses on African American patients and readiness to make decisions about kidney disease. This study explored African American patients who were diagnosed with end-stage renal disease, looking at interventions, effectiveness, communication, and ways to promote and improve ratings of patient readiness, and patient-centered care. Furthermore, quantitative, and qualitative research was the method selected to design and test information focusing on health care decision-making, effectiveness, communication, involvement, interventions, and financial assistance needed for the African American patients with end-stage renal disease.

As a result, Ephraim's (2012) study presented the perception of African Americans being less likely than European American counterparts to be prepared for end-of-life planning and wanted to prolong medical treatments. The study also suggests African Americans with end-stage renal disease have trouble with indirect cost, being donors, and shared or informed decision-making. Recruitment of the Ephraim's participants included those from an academically affiliated community-based dialysis center in Baltimore, MD.

A practical guide that focused on patients diagnosed with kidney disease and was near the end-of-life was written by Bansal and Schell (2018). Additionally, this study will focus on advanced care planning and efforts to improve patient-centered care. Additionally, a quantitative study by Wachterman et al. (2017) focused on older Americans who were older than 70 years of age with end-stage renal disease. This study will explore end-of-life experience, assessing symptoms among older patients near the end of life. The study used a data source titled health and retirement study, using a sample of 1883 participants who passed with cancer or end-stage renal disease between the years of 2000 and 2010. Additionally, a study by Crews et al. (2018) centered on race and ethnicity risks for patients with end-stage renal disease and dietary concerns during the end-of-life period. This article gave insight into the risk model accounting for death. The researcher used a quantitative method and a population of 1,123 non-Hispanic black (NHB), and non-Hispanic White (NHW).

Phillips (2018) introduced clear points regarding chronic kidney disease and the patient experience regarding advanced care planning during the end-of-life within a hospital or community-based setting. The study used a survey to collect data for sampling non-probability and consecutive sampling (*n* = 133). Additionally, the study shared three different insights on patients who did not identify with having a health condition and those patients who felt comfortable to talk about end-of-life planning opposed to those who waited until their condition worsened.

Definitions

Elderly is defined as 55 years of age and older who have end-stage renal disease.

Advance care planning is defined as a tool used for whether the decedents had written end-of-life care instructions (yes or no), whether treatment decisions need to be made in the final days of life (yes or no), and whether the elderly patients were able to participate in these decisions (e.g., medical treatment, spiritual wishes, resuscitate, nutrition, and family involvement; Wachterman et al., 2017).

African American is defined as people of African American descent who are living in the United States and relate as Black Americans (Merriam, 1991).

European American is defined as people of European American descent with ancestry from the Northern Region of England, Ireland, Iceland, and Norway (Merriam, 1991).

Hispanic is defined as people who are of Hispanic American descent and are Latin American living in the United States relating to Spanish speaking countries (e.g., Mexico, Cuba, Puerto Rico, or Spain; Merriam, 1991).

End-of-life decisions refer to a supportive care plan of action given to the terminally ill patient or healthy patient to document health care treatment, appoint a designated health care maker for making decisions in the event the patient is unable to speak, to extend quality of life for the best quality of care during the end-of-life period.

End-stage renal disease is Stage 5 of chronic kidney disease that decreases the normal function of filtration in the body for removing waste and urine. End-stage renal disease is serious and is considered life-threatening.

Leaders/leadership is defined as leaders who drive and make decisions to help healthcare patients in a healthcare organization. These leaders (e.g., physician-in-chief, chief medical administrators, department medicine managers, physician module leaders, chief nursing officer, chief medical officer, chief of managed care, chief legal officer, chief health information officer, chief executive officer) are the leaders who help shape healthcare policies and processes in the United States.

Documented treatment decisions are a plan of action used when a patient has been diagnosed as terminally ill and near the end of life. Most importantly, documented treatment decisions are used to honor the patient wishes for making healthcare decisions for medication, dietary needs, resuscitation, and quality of care near the end of life.

Assumptions

According to the United States Renal Data system, there are approximately more than 661,000 Americans who are 55 and older with end-stage renal disease and the African American population is considered 3.7 times greater for being diagnosed as opposed to European American (Harding, 2017). However, according to the journal of Chronic Kidney Disease in the United States, Hispanic Americans make up 14% of the 661,000 individuals with end-stage renal disease (Death, 2019).

Additionally, end-stage renal disease among the African American population increased by 30% (Harding, 2017), and is considered a large group in the United States population (Ladin, 2018). One important limitation is there is limited research on end-of-life and family engagement. Therefore, this research will focus on the low rates of advance care directives and rates of health care treatments at the end of life.

The results of this study may assist healthcare leaders to implement practices and policies for culturally responsive care for elderly patients with end-stage renal disease. A plan of the next steps will give the family, health care administrators, and executive leadership time to prepare advocacy plans for the patient. According to previous studies, the end-of-life experience should honor the patient’s wishes (Grant, 2017). The perception of gaps and barriers for African Americans is that they have lower rates of being prepared, family engagement and require financial assistance to overcome the treatments of end-stage renal disease compared to Hispanic and European Americans (Bansal, 2017).

This doctoral research study involves a random sampling of elderly African American, Hispanic, and European Americans who are 55 years of age and older with end-stage renal disease who reside in the United States. The Health and Retirement Study database contains this information (2018). Details about the sampling strategy are contained in the methodology section. Research on the topic of leadership and end-of-life planning among elderly patients with end-stage renal disease, operationalized as African American, Hispanic, and European American, requires further research to improve communication between the patient with end-stage renal disease, the physicians, family, and hemodialysis staff.

The improved communication among these groups could improve participation in advanced care planning and can be used as a guide for quality and preferences at the end-of-life, to better understand the gaps and barriers to each rate of advanced care directives, and rates of health care treatments among older adults who are operationalized as African American, Hispanic, and European American with end-stage renal disease is important to determine, and analyze if there is a lack of support at the end-of-life planning process, and if families struggle with working together on deciding what is best for the patient who has advanced illness upon hospice and hospital readmission so that patients can benefit before it is too late (Eneanya, 2015).

Additionally, the HBM may have limitations for the specific ordering of the variables, which is a significant part of the research for testing the behaviors of the independent variable advanced illness and the dependent variables healthcare decision-making, and hospice utilization (Champion & Skinner, 2008).

Scope and Delimitations

It is acknowledged that there may be several delimitations for this quantitative study. However, the findings in this study will take further investigation that involves exploring leadership and elderly patients with end-stage renal disease. Studying this population of leadership and elderly patients diagnosed with end-stage renal disease may require additional data sources to determine whether the patient and family are engaged with the process of end-of-life planning for a better quality of care.

Significance, Summary, and Conclusions

The requirements of the Joint Commission 2019 require healthcare leaders to understand and know the principles of care for embracing quality principles of treatments for the patient exactly as written at the end of life. Essentially, healthcare leaders are required to have ethical relationships for positive outcomes based on the quality of care, patient safety, and organizational cost (VandeRiet, 2019). Furthermore, the Joint Commission requires healthcare leaders to honor and respect patient rights for culturally appropriate care that includes being informed of treatment, having the right to refuse pain medications, and being listened to with courtesy and respect (Death, 2019). According to GCHM (2015), leaders are responsible for improving the health of populations, promoting, and enhancing leadership and management policies, and practices in healthcare. Equally, leadership needs to be able to clearly and concisely conduct ethical and professional standards for the improvement of quality care during the end-of-life process (GCHM, 2015).

Healthcare leaders identified that more than 8 million people in the United States possess no kidney function (Centers for Disease Control and Prevention, 2015). They also noted that few of these patients created an end-of-life plan making it difficult to provide patient-centered care meeting their individual needs (Death, 2019). Previous studies identified low rates of advanced care directives contributing to high rates of health care treatments at the end-of-life, especially among older adults who are African American as opposed to Hispanic and European Americans (Boucher, 2016).

The results of this study may empower the executive leadership to understand better-advanced care planning and end-of-life decision-making for a better quality of life, as it relates to racial and ethnic disparities for patients diagnosed with advanced illness to deliver better patient-centered care. Researchers who explored end-of-life planning disclosed that African Americans participate less in health care decision-making, compared to Hispanic and European Americans, which results in a lower quality of life and the healthcare staff making the end-of-life process decisions, as opposed to the patient or the patient’s family (Washington, 2016).

The findings can lead to positive social change for value-based care at the end-of-life that will drive best practices for quality of care and standardized approaches for person-centered care in the United States healthcare system (Illness, 2017). Additionally, there are several ways in which this research could contribute to the identified practice and professional practice in a healthcare organization and positive social change. The first way leaders could use this information is implemented practices and policies for adapting culturally responsive care during the end-of-life. The second way would be the cost of care may be lower; medical errors may be avoided by respecting the patient's wishes; physicians and healthcare administrators may have improved communication with both the patient and their family member. The third way would be that this study may help physicians and healthcare administrators obtain better appreciation for cultural differences in end-of-life planning.

End-of-life planning is important to executive leaders for the improvement of care at the end-of-life and improving infrastructures (e.g., accessible care, training systems, and reliable resources) that will ultimately lead to reducing disparities in healthcare, which would be a positive effect on social change in the United States. The improvements in health practices noted above could result in the development of standard practices that are relevant to patients with advanced illnesses (Illness, 2017). Additionally, when someone's loved one is diagnosed with advanced illness and is considered terminally ill, end-of-life care is important for implementing practices and policies for adapting culturally responsive care to the adult patient during the end-of-life period.

The specific variables used in this study, ethnicity status and end-of-life care instructions, will assist in addressing the ethnicity status gap help leaders implement practices and policies for culturally responsive care for elderly patients with end-stage renal disease. A plan of the next steps may give the family, health care administrators, and executive leadership time to prepare advocacy plans for the patient. According to recent studies, the end-of-life experience should honor the patient’s wishes (Grant, 2017). However, with low completion of advanced care directives, the results of this study may positively encourage executive leaders to create standard practices, which may change how patients feel about completing the advanced care directive, and potentially drive more patients to complete an advanced care directive, which will save time, energy, and cost for the family members, and the health care organization (Bansal, 2018).

The specific positive social change may be that executive health care leaders (i.e., physicians, administrators, managers) ensure the patient’s wishes for end-of-life are on file in the patient’s health record and followed (Boucher, 2016). Furthermore, the results from this study may create a culture where executive leadership ensures that providers respect and listen to the patient's wishes during the end-of-life experience for better treatment and can inform leaders to create policies that will facilitate discussions for end-of-life planning, resulting in meeting leadership requirements identified by accrediting and regulatory standards.

End-of-life planning should become customary in healthcare organizations for the delivery of best care, patient preferences, and to shape treatment choices and plans for the elderly patient with an advanced illness. Phillips, MacNab, and Loewen (2018) identified a gap in the literature related to advanced care planning and patients who were diagnosed with end-stage renal disease. The research literature reported the health beliefs of the patients and how miscommunication occurred between the patient and healthcare provider about patient preferences, and experience during the end-of-life (Boucher, 2016).

Communication and personal beliefs are the variables derived from the literature; furthermore, recent research supports literature gaps related to health beliefs and the lack of communication, knowledge about end-of-life planning among older African American patients who were diagnosed with an advanced illness who lacked an advanced care directive on file at their selected health care organization during the end-of-life (Wachterman et al. (2017).

Specifically, researchers identified that there is a gap among those who faced treatment at the end-of-life, but not knowing if the influencing behaviors are related to whether there were differences among ethnic groups on whether the decedents had written end-of-life care instructions, whether treatment decisions need to be made in the final days of life, and whether the elderly patients were able to participate in their end-of-life decisions (Wachterman et al., 2017).

The leaders of healthcare play an essential role in advancing new policies, workflows, and process changes, as it relates to a better quality of service and care. The implications for positive social change for healthcare administrators will include awareness and practical changes for creating a standard workflow for healthcare decision-making for clinical teams and processes to increase the completion rates of advanced care directives among the older population.

Additionally, this study may contribute to the understanding that all age groups should have an advanced care directive completed and on file, which will help improve quality of life, and provide the best understanding of healthcare decision-making, and respecting the patient’s wishes, which may reduce errors in treatment during the end-of-life period. The end of life is a sensitive topic of conversation for some people who are in the midst of planning. However, most people do not or have not thought about having these respectful conversations and, as a result, go without having conversations with family, which results in aggressive treatments among those who are diagnosed with advanced illness (Grant, 2017).

The health belief model (HBM) is an explanatory communication research tool that can assist with the mediation of understanding the relationship of why most people have not thought or have had the end-of-life conversation (Becker, 1974; Champion & Skinner, 2008; Rosenstock, 1974). The challenge healthcare leaders face is understanding how to gain the engagement of the surrounding culture in the healthcare organization to embrace new approaches to engage the patient and family in the conversation of end-of-life planning, so that the information can be submitted into the patient's healthcare records.

The long-term benefits for society are the social change that will evolve through the end-of-life planning process in the healthcare organization with the improvement of quality of care, communication, right treatments, and respecting the patient's wishes during the end-of-life period. For health care leaders, the social change is the communication practices that will be used to treat the patient during the end of life, which allows a legal transactional approach for the physicians, medical staff, and administrators to follow for the best care visibly.

The acquisition of a health care directive for the file provides executive leaders a legal tool to communicate the formal wishes of the patient diagnosed with advanced illness in the event of incapacity during the end-of-life phase of treatment. The specific problem is that African Americans are less likely to participate than other racial or ethnic groups (e.g., Hispanic and European Americans) with end-of-life planning and identifying a health care decision-maker to file upon hospice utilization or readmission to the hospital (Chen, 2018).

Section 2: Research Design and Data Collection

Introduction

Healthcare leaders need more information about end-of-life planning in order to meet the needs of the patient delivery of care. The purpose of the proposed quantitative causal-comparative research study is to examine the population of elderly patients with end-stage renal disease, examining whether there is a relationship between ethnicity status and advanced care planning and end-of-life decision-making among those who are 55 years of age and older. Ethnicity is defined as African Americans, Hispanics, and European Americans living in the United States (Crews, 2018).

Advance care planning and end-of-life decision-making is defined as (a) whether the decedents had written end-of-life care instructions (yes or no), (b) whether treatment decisions need to be made in the final days of life (yes or no), and (c) whether the elderly patients were able to participate in these decisions (e.g., medical treatment, spiritual wishes, resuscitate, nutrition, and family involvement.). In this study, the dichotomous independent variables are African Americans, Hispanics, and European Americans, while the categorical dependent variable is advance care planning and end-of-life decision-making. I used multiple logistic regression to evaluate the research questions and intervening variables of communication between patient and doctor, and health beliefs of patients who may not want to participate.

Research and Design Rationale

The secondary data set for this study came from the health and retirement study, which is a study of a longitudinal project that focused on the aging society and social security of administration (HRS The Health and Retirement Study, 2018). This dataset contains a random sampling of individuals who are 55 years of age and older, have end-stage renal disease, and reside in the United States. Specific variables and dataset for this study included ethnicity status and end-of-life care instructions for treatments focusing on end-stage renal disease patients, and the use of written life care instructions, patient able to participate in end-of-life care instructions, and patient able to participate in care decisions.

The quantitative causal-comparative research design was used in this doctoral study. The purpose of this study was to examine the population of elderly patients with end-stage renal disease, examining whether there is a relationship between ethnicity status and advanced care planning and end-of-life decision-making among those who are 55 years of age and older.

The quantitative design was chosen for three reasons. First, the quantitative methodology is used when the goal is to measure variables numerically using commonly accepted measures of the physical world (Creswell, 2018; Hair et al., 2018; Leedy & Omrod, 2018). Second, the quantitative methodology is used when research questions are examined through the statistical examination of the data (Creswell, 2018; Hair et al., 2018; Leedy & Omrod, 2018). Finally, the quantitative methodology is employed when the goal of research generalizes the findings to a larger population from which the study sample is derived (Creswell, 2018; Hair et al., 2018; Leedy & Omrod, 2018). Since ethnicity is coded as a numeric variable and advance care planning and end-of-life decision-making are also numeric variables, the quantitative methodology was appropriate for this study. The qualitative methodology was inappropriate for this study because it cannot determine statistically significant relationships between variables, and it answers “how” and “why” questions, whereas the quantitative methodology answers “what” questions.

In addition, the quantitative study uses a relatively large sample size, which allows for the projectability of results to the target population (Creswell, 2018; Hair et al., 2018; Leedy & Omrod, 2018). The causal-comparative design examines the numeric relationship between variables of interest as they exist in a defined population at a single point in time or over a short period of time (e.g., calendar year; Creswell, 2018; Hair et al., 2018; Leedy & Omrod, 2018).

The current study, as mentioned earlier, examined whether a numeric variable, end-of-life planning status, predicts another numeric variable, advance care planning and end-of-life decision-making among those who are 55 years of age and older. End-of-life planning status, advance care planning, and end-of-life decision-making are not manipulated variables, but variables that already exist in the defined population of those 55 years or older.

Therefore, the causal-comparative research design was appropriate for this study. The experimental and quasi-experimental designs are not appropriate for this study as there is no pre and posttest or control group. Finally, the causal-comparative design was appropriate because other studies in this field also used this design (Grant, 2017; Illness, 2017; Wachterman et al., 2017; Washington, 2016).

Methodology

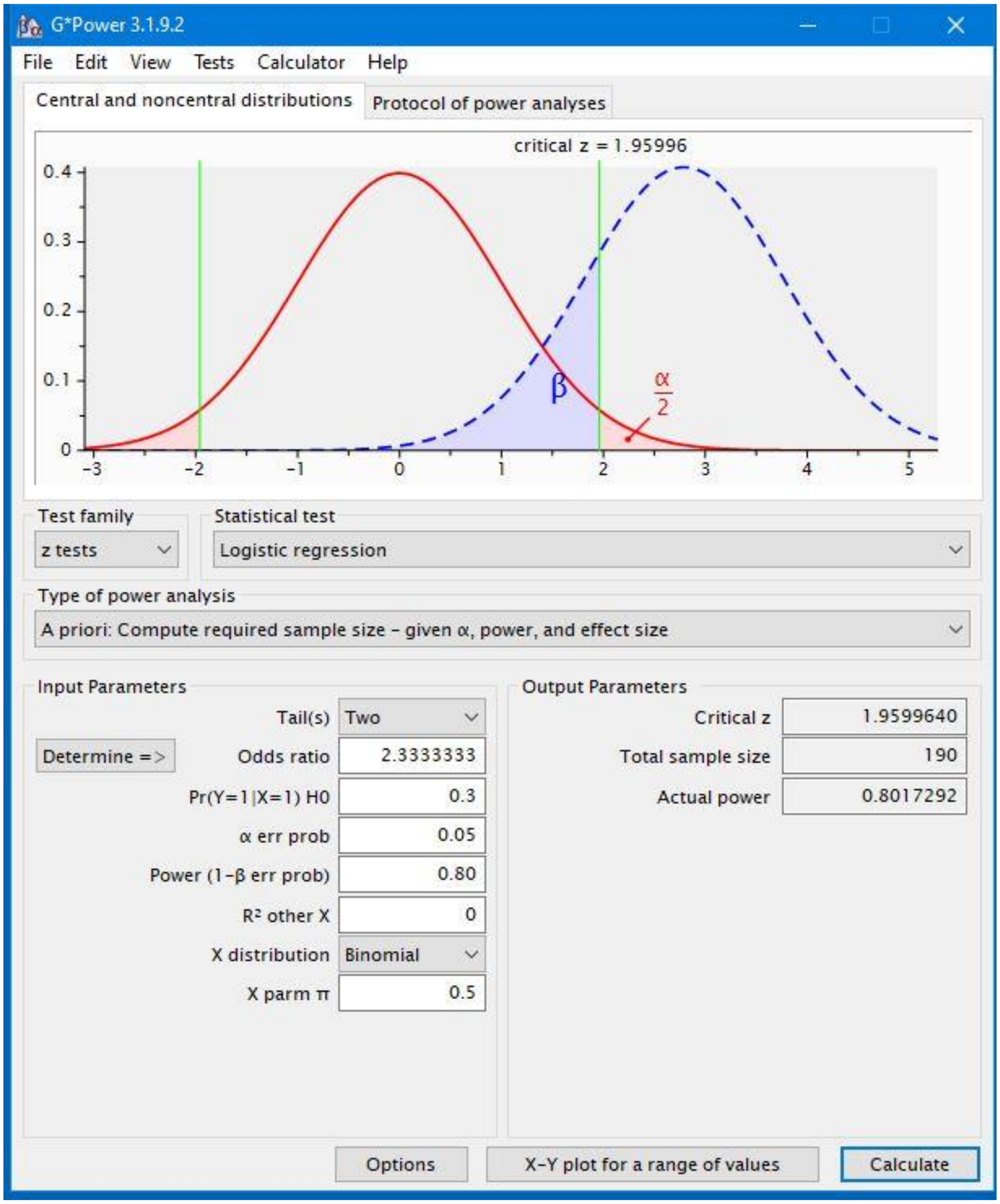
Population

The target population consists of individuals 55 years of age and older who have been diagnosed with end-stage renal disease in the United States. Additionally, the target population is limited to those who are European American, African American, and Hispanic. According to the United States Renal Data system, more than 661,000 Americans age 55 and older have end-stage renal disease, and the African American population is 3.7 times more likely of being diagnosed as opposed to European American (Harding, 2017). However, Hispanic Americans makes up 14% of the population with end-stage renal disease (Death, 2019).

Sampling and Sampling Procedures

During the planning phase, the target was a sample size of 13,500 individuals living in 8,000 households, screened from approximately 70,000 household addresses, with a response rate of 80% and an eligibility rate of 19% men. In married-couple households, there are also a slightly larger number of women than men because, in those few cases where one of the couples refused to participate, men were more likely to refuse. HRS has a little over 2,000 African Americans, almost 1,200 Hispanics, and 9,416 European Americans. About 63% of the samples are working for pay, some 12% are already retired, about 9% are disabled, and another 15% are homemakers.

To determine the minimum sample size needed for this study, I conducted a power analysis using G*Power (Erdfelder, Faul, & Buchner. 1996). Sample size was calculated for a binary logistic regression with one binary predictor variable. Statistical power was calculated with a medium effect size, a statistical power of .80, and error probability of .05. Based on these values, the minimum sample size to have an 80% chance of detecting a significant effect is 190 (see Figure 1).



Test family: z tests

Statistical test: Logistic regression

Type of power analysis: A priori: Compute required sample size – given α, power, and effect size

Input Parameters

Tail(s)	Two
Odds ratio	2.3333333
Pr(Y=1|X=1) H0	0.3
α err prob	0.05
Power (1-β err prob)	0.80
R^2 other X	0
X distribution	Binomial
X parm π	0.5

Output Parameters

Critical z	1.9599640
Total sample size	190
Actual power	0.8017292

Figure 1. Screen shot of G*Power power analysis.

Instrumentation and Operationalization of Constructs

Data was obtained from the health and retirement study (HRS), a nationally representative longitudinal survey of community-dwelling adults aged 51 years or older (HRS, 2019). Every two years until their death, HRS study participants complete a core interview (Juster & Suzman, 1995). Then after each participant's death, a family member or some other proxy informant who is knowledgeable about the deceased participant complete the exit interview. This study focused on the exit interviews, and the response rates ranged from 85% to 92% across four study waves between 2010 and 2016 (HRS, 2019).

The HRS survey contained several sections. These included sections on demographics, physical health, and functioning, housing and mobility, family structure, current job, past job, work history, disability, retirement plans, net worth, and insurance. For this study, the sections of interest were demographics, physical health, and functioning, and the exit interview sections advanced care planning/decision-making and major illness that led to your loved one's death. The survey took about 60 minutes to complete.

Operationalization

Across the three research questions, there was one independent variable, ethnicity, and three separate dependent variables related to advance care planning/decision-making. The first research question asked, to what extent is ethnicity status a significant predictor of whether the decedents had written end-of-life care instructions on file among those 55-years of age and older who have end-stage renal disease. Ethnicity is a nominal variable and operationalized as African American, European American, and Hispanic, where each ethnicity is assigned a numeric value. The dependent variable, whether the decedents had written end-of-life care instructions on file, was operationalized as a dichotomous variable, where 0 was no, and 1, was yes.

The second research question asked, to what extent is ethnicity status a significant predictor of whether documented treatment decisions in the final days of life, defined as whether decisions needed to be made in the final days of life among those who are 55 years of age and older who have end-stage renal disease. Again, ethnicity is operationalized as African American, European American, and Hispanic. The dependent variable, whether decisions needed to be made in the final days of life, where 0 is no and 1, is yes.

For the third research question, to what extent is ethnicity, operationalized as African American, Hispanic, and European American status a significant predictor of whether the elderly patients were able to participate in treatment decisions among those who are 55-years of age and older who have end-stage renal disease, ethnicity remained the same. The dependent variable, whether the elderly patients were able to participate in treatment decisions, was coded as 0 for no, and 1 for yes. All the dependent variables in the three research questions are dichotomous, where 0 is no and 1, is yes.

Data Analysis Plan

The data analysis process consisted of three phases, the data preparation phase, the preliminary analysis phase, and the primary analysis phase. The data preparation phase consisted of the data first being input into SPSS v23 (IBM SPSS Statistics, 2019).

After inputting the data into SPSS, I performed frequency descriptive statistics to evaluate if there were any missing data or data errors. No data errors were found in data file.

Since the data is obtained from a secondary source, the HRS study, it is not anticipated that there will many missing values or data errors, if at all. After the data is checked for errors and missing values, any new variables or variable recoding that needs to be done is completed at this point. Once this is completed, the data preparation phase is concluded.

Next is the preliminary analysis phase. During this phase, the tests of parametric assumptions are conducted. Since the research questions are about prediction, and the dependent variable is dichotomous, logistic regression is performed to address the three research questions. The parametric assumptions to be tested for the logistic regression are linearity of the logit, and multicollinearity (Field, 2017, Pallant, 2016). To test for linearity, first, the log of the ethnicity variable is computed. Then, the log of the independent variables is multiplied by the independent variable value to create an interaction term.

The interaction term is added to the logistic regression. If the interaction term is significant, then the assumption of linearity is violated (Field, 2017; Pallant, 2016). Since there is only one independent variable in the analysis, there is no issue with multi-collinearity. Finally, primary analysis is conducted to address the three research questions. The logistic regression is conducted three times. If the *p* value of the logistic regression is less than .05, then the model as-a-whole is significant.

If the *p* value is less than .05, then the odds ratios were reviewed to determine which ethnic groups make a significant contribution to the model. The target population consists of those 55-years-of-age and older who have been diagnosed with end-stage renal disease in the United States. Additionally, the target population is limited to those who are European American African American and Hispanic.

Threats to Validity

Internal validity refers to whether the conclusions that are reached in the study are accurate. One of the threats of internal validity is maturation. It may be that the passing of time and the progression of their end-stage renal disease affects their ability to participate in their end of life care instructions. External validity refers to the generalizability of results. There is oversampling for African Americans and Hispanics that was 2:1 relative to European Americans for the HRS study. As a result, the results may not be projectable to the total U.S population.

Ethical Procedures

The data from the health and retirement study (HRS) is publicly available for download from the HRS web site. All that is needed is to locate the desired databased via the search tool on the web site. The data file contains no personally identifiable information in the file, so there is no concern for violations of confidentiality. The data will be stored in a secure, password-protected computer that is not connected to the internet. All protocols of the IRB are followed to ensure that there are no violations in ethics or IRB standards. Additionally, respondents will not be able to take the study until they have accepted the informed consent agreement described above. Additionally, respondents under the age of 18, inmates, and pregnant patients with end-stage renal disease will not be included in this study.

Summary

The purpose of this quantitative casual-comparative research study is to examine the relationship between ethnicity status, operationalized as African American, Hispanic, and European American, and advanced care planning and end-of-life decision-making among those who are 55 years of age and older (Death, 2019). Data were obtained from the health and retirement study (HRS), a nationally representative longitudinal survey of community-dwelling adults aged 51 years or older.

Every two years until their death, HRS study participants complete a core interview (Juster & Suzman, 1995). The data analysis process consists of three phases, the data preparation phase, the preliminary analysis phase, and the primary analysis phase. The data preparation phase consists of the data first being input into SPSS v23 (IBM SPSS Statistics, 2019). In the next section, the results of the data are reported in detail.

Section 3: Presentations of the Results and Findings

Introduction

The purpose of this quantitative causal-comparative research study is to examine the population of elderly patients with end-stage renal disease, examining whether there is a relationship between ethnicity status and advance care planning and end-of-life decision-making among those who are 55 years of age and older. Ethnicity is defined as African Americans, Hispanics, and European Americans living in the United States (Crews, 2018).

There were three research questions in this study. The first research question asks, to what extent is ethnicity status, operationalized as African American, Hispanic, and European American, a significant predictor of whether the decedents had written end-of-life care instructions on file among those who are 55 years of age and older who have end-stage renal disease? The second research question asks, to what extent is ethnicity status, operationalized as African American, Hispanic, and European American, a significant predictor of whether documented treatment decisions in the final days of life, defined as whether decisions needed to be made in the final days of life among those who are 55 years of age and older who have end-stage renal disease? The third research question asks, to what extent is ethnicity status, operationalized as African American, Hispanic, and European American, a significant predictor of whether the elderly patients were able to participate in treatment decisions among those who are 55 years of age and older who have end-stage renal disease?

This section of the dissertation consists of three subsections. Data Collection Of Secondary Data Set, Results, and Summary. First, in Data Collection of Secondary Data Set, I review the time frame for data collection, descriptive statistics of the demographic data, and a description of the sample. The second subsection, Results, provides the results of the statistical analyses. In this subsection, the three null hypotheses are tested. The first null hypothesis tested is that ethnicity status, operationalized as African American, Hispanic, and European American, is not a significant predictor of whether the decedents had written end-of-life care instructions. The second null hypothesis tested is that ethnicity status, operationalized as African American, Hispanic, and European American, is not a significant predictor whether documented treatment decisions needed to be made in the final days of life among those who are 55 years of age and older. The final null hypothesis tested is that ethnicity status, operationalized as African American, Hispanic, and European American, is not a significant predictor of a significant predictor of whether the elderly patients were able to participate in these decisions among those who are 55 years of age and older. Finally, this section concludes by summarizing the answers to the research and transitioning to Section 4.

Data Collection of Secondary Data Set

Data Collection Timeframe

Data were obtained from the HRS, a nationally representative longitudinal survey of community-dwelling adults aged 55 years or older. Every 2 years until their death, HRS study participants completed a core interview (Juster & Suzman, 1995). Then after each participant’s death, a family member or some other proxy informant who was knowledgeable about the deceased participant completed the exit interview. This study focused on the exit interviews, the response rates for which ranged from 85% to 92% across four study waves between 2010 and 2016 (HRS, 2019). The secondary data set I obtained included these four waves of data from 2010, 2012, 2014, and 2016. I downloaded these files and combined them into one SPSS data file. The variables used from the data file were ethnicity, marital status, church attendance, cause of death, having written end-of-life instructions, participation of the elderly patient in their health care decisions, and end-of-life instructions used in the final days.

There was one discrepancy in the use of the secondary data set from what was planned. Before filtering the data for persons who died from kidney disease, there were 13 Hispanics, 4,172 European American, and 1,013 African American in the sample from the four waves of data. After filtering the data for people who died from kidney disease, there were 1,010 European American and 289 African American. Therefore, Hispanics were excluded from the analysis. It should be noted that the selection criterion was the same criteria used in Wachterman et al.’s (2017) study.

Sample Representativeness

There was a total of 4,172 European American in the study, of whom 1,010 (24.2%) died from kidney disease. Comparably, there were 1,013 African American in the sample and 289 (28.6%) who died from kidney disease. Previous research indicated that the African American population is diagnosed with kidney disease at a rate 3.7 times greater than that of European Americans (Harding, 2017). Based on this information, the current sample does not represent the proportional representation found in the population in the United States. Therefore, the sample of the current study is not representative of the population.

Results

The purpose of this quantitative causal-comparative research study was to examine the population of elderly patients with end-stage renal disease, examining whether there is a relationship between ethnicity status and advance care planning and end-of-life decision-making among those who are 55 years of age and older. This section will present the sample of the descriptive statics, test of statistical assumptions and the summary of treatment of decisions. Additionally, this section provides results of ethnicity defined as African Americans, Hispanics, and European Americans living in the United States (Crews, 2018).

Sample Descriptive Statistics

The sample consisted of those from the health and retirement study (HRS) who died from kidney disease between the 2010 and 2016 waves. There were a total of 1299 respondents in this study, of whom 77.8% were European American and 22.2% were African American. A majority (50.3%) of those in the study were married at the time of death and under half (43.1%) had written end-of-life instructions. However, over 75% of the respondents in the study had end-of-life instructions that were not used in the final days of life. Finally, over 30% of participants attended church at least once a week before they died (see Table 2).

Table 2

Demographic Descriptive Statistics

	European American		African American		Total	
	N	%	*N*	%	*N*	%
Marital Status						
Married	431	42.8%	222	76.8%	653	50.3%
Separated	14	1.4%	5	1.7%	19	1.5%
Divorced	133	13.2%	22	7.6%	155	12.0%
Widowed	379	37.6%	33	11.4%	412	31.8%
Never married	45	4.5%	7	2.4%	52	4.0%
Other	6	0.6%	0	0.0%	6	0.5%
Attend Religious Service						
More than once a week	71	7.2%	28	10.0%	99	7.8%
Once a week	216	21.9%	71	25.3%	287	22.6%
Two or three times a month	101	10.2%	24	8.5%	125	9.9%
One or more times a year	178	18.0%	42	14.9%	220	17.3%
Not at all	422	42.7%	116	42.4%	538	42.4%
Had written end of life instructions						
Yes	195	23.8%	61	25.0%	462	43.1%
No	624	76.2%	183	75.9%	612	56.9%
End-of-life instructions used in final days						
Yes	498	50.1	125	43.7%	256	24.1%
No	496	49.9	161	56.3%	807	75.9%

Test of Statistical Assumptions

There are three assumptions of the logistic regression. They are linearity of the logit for continuous variables, no multicollinearity, and lack of strongly influential outliers (Field, 2017; Tabachnick & Fidell, 2018). In this study, there is a single predictor variable, ethnicity, and it is categorical. It contains two groups: African American and European American. Because there is only one predictor variable, there is no issue with multicollinearity. Additionally, because the predictor variable is categorical, there is no violation in the assumption of linearity of the logic for continuous variables. There is also no violation in the assumption of strongly influential outliers because the predictor variable is not continuous. Therefore, there is no violation in any of the assumptions of the logistic regression.

Results of Statistical Analysis

RQ1: To what extent is ethnicity status, operationalized as African American and European American, a significant predictor of whether the decedents had written end-of-life care instructions on file among those who are 55 years of age and older who have end-stage renal disease?

In the first logistic regression analysis, the outcome variable is, decedents had written end-of-life instructions, where 0 was no and 1 was yes. The categorical predictor variable was ethnicity, where 1 was European American and 2 was African American. The null hypothesis tested in this analysis was, ethnicity status, operationalized as African American and European American, is not a significant predictor of whether the decedents had written end-of-life care instructions. The results of the logistic regression indicated that the model was not statistically significant, as the p value was less than .05, χ^2 (1) = .034, p = .85. The results indicated that the model was not able to distinguish between those who had written end-of-life care instructions and those who did not. Therefore, the null hypothesis was not rejected (see Table 3).

Table 3

Logistic Regression Predicting Whether Descendants had Written End-Of-Life Instructions

							95% C.I.for EXP(B)	
Participation	*B*	*S.E.*	*Wald*	*df*	*Sig.*	*Exp(B)*	*Lower*	*Upper*
Had EOL Instructions	-.063	.134	.034	1	.85	1.03	.79	1.33

RQ2: To what extent is ethnicity status, operationalized as African American, and European American, a significant predictor of whether documented treatment decisions in the final days of life, defined as whether decisions needed to be made in the final days of life among those who are 55 years of age and older who have end-stage renal disease?

The second research question used the categorical outcome variable, whether documented treatment decisions were used in the final days, where 0 was no, and 1 was yes. The categorical predictor variable was ethnicity, where 1 was European American and 2 was African American. The null hypothesis tested in this analysis was, ethnicity status, operationalized as African American, and European American, is not a significant predictor whether documented treatment decisions needed to be made in the final days of life among those who are 55 years of age and older. Results of the logistic regression revealed that the model was not significant, χ^2 (1) = 3.64, *p* = .06, indicating that the model was not able to distinguish between those who used documented treatment decisions in the final days versus those who did not. As a result, the null hypothesis was not rejected. See Table 4.

Table 4

Logistic Regression Predicting Whether Documented Treatment Decisions Were Used in the Final Days

Participation	*B*	*S.E.*	*Wald*	*df*	*Sig.*	*Exp(B)*	*95% C.I.for EXP(B)*	
							Lower	*Upper*
EOL Instructions Used in Final Days	.257	.135	3.63	1	.06	1.29	.99	1.69

RQ3: To what extent is ethnicity status, operationalized as African American, Hispanic, and European American, a significant predictor of whether the elderly patients were able to participate in treatment decisions among those who are 55 years of age and older who have end-stage renal disease?

The final research question contains the categorical outcome variable, elderly patients were able to participate in treatment decisions, where 0 was no, and 1 was yes. The categorical predictor variable was ethnicity, where 1 was European American and 2 was African American. The null hypothesis under investigation is, ethnicity status, operationalized as African American, and European American, is not a significant predictor of a significant predictor of whether the elderly patients were able to participate in these decisions among those who are 55 years of age and older. Results of the logistic regression indicated that the model was not significant, χ^2 (1) = 2.94, p = .09, indicating that the model was not able to distinguish between those elderly patients who participated in treatment decisions in the final days versus those who did not. As a result, the null hypothesis was not rejected.

Table 5

Logistic Regression Predicting Whether Elderly Patients Were Able to Participate in Treatment Decisions

							95% C.I.for EXP(B)	
Participation	*B*	*S.E.*	*Wald*	*df*	*Sig.*	*Exp(B)*	*Lower*	*Upper*
Elderly patients were able to participate in treatment decisions	.378	.22	2.89	1	.09	1.46	.94	2.26

Summary

There were three research questions under investigation in this study related African American, Hispanics and European American. The results of the first research question indicated that the model was not statistically significant, $\chi2$ (1) = .034, p = .85, indicating that the model was not able to distinguish between those who had written end-of-life care instructions and those who did not. Therefore, the null hypothesis was not rejected.

The results of the second research question, indicated that the model was not significant, $\chi2$ (1) = 3.64, *p* = .06, indicating that the model was not able to distinguish between those who used documented treatment decisions in the final days versus those who did not. As a result, the null hypothesis was not rejected. Finally, the results of the third research question indicted that, that the model was not significant, $\chi2$ (1) = 2.94, *p* = .09, indicating that the model was not able to distinguish between those elderly patients who participated in treatment decisions in the final days versus those who did not. As a result, the null hypothesis was not rejected. In the next section, the results of the three-research question are discussed in the context of theoretical framework and the research discussed in Section 2.

Section 4: Application to Social Professional Practice and Implications for Social Change

Introduction

The purpose of this section is threefold. First, I interpret the findings of the study in the context of the theoretical framework and the research discussed in previous sections. Next, I discuss the limitations. The limitations focus on issues that limit generalizability, validity, and reliability. Finally, this section concludes with recommendations for future research, as well as recommendations for future practice,

Summary of Results

The first research question asked, “To what extent is ethnicity status, operationalized as African American and European American, a significant predictor of whether the decedents had written end-of-life care instructions on file among those who are 55-years-of-age and older who have end-stage renal disease?” The results indicated that ethnicity status was not a significant predictor of whether someone had written end-of-life care instructions or not. The second research question asked, “To what extent is ethnicity status, operationalized as African American and European American, a significant predictor of whether documented treatment decisions in the final days of life, defined as whether decisions needed to be made in the final days of life among those who are 55 years of age and older who have end-stage renal disease?” Results indicated that the model was not able to distinguish between those who used documented treatment decisions in the final days versus those who did not. Finally, the third research question asked, “To what extent is ethnicity status, operationalized as African American, , and European American, a significant predictor of whether the elderly patients were able to participate in treatment decisions among those who are 55 years of age and older who have end-stage renal disease?” Results indicated that the model was not able to distinguish between those elderly patients who participated in treatment decisions in the final days versus those who did not.

Interpretation of Findings

Ephraim (2012) conducted a mixed-method study examining African Americans with end-stage renal disease or who were diagnosed with a terminal illness (e.g., cancer, HIV, diabetes). The results suggested that African Americans had less engagement than other racial or ethnic groups. Furthermore, additional research supports that more European Americans (81.5%) with advance care directives and engagement than African Americans (8.6%), and Hispanics (6.9%; Crews, 2018).

The Ephraim (2012) presented the perception of African Americans as being less likely than their European American counterparts to be prepared for end-of-life planning and more likely to want to prolong medical treatments. Based on these findings, it was expected that ethnicity status would be a significant predictor of whether African Americans and European Americans had written end-of-life care instructions. Results of the study indicated that ethnicity status was not a significant predictor of whether African Americans and European Americans had written end-of-life care instructions. Therefore, this study did not support what was expected based on the Ephraim’s findings.

It was also expected that ethnicity status would be a significant predictor of whether African Americans and European Americans would have documented treatment decisions in the final days of life. The results of the study did not support what was expected, as the results indicated that ethnicity status was not a significant predictor of whether African Americans and European Americans would have documented treatment decisions in the final days of life. Finally, based on Ephraim's (2012) study, it was expected that ethnicity status would be a significant predictor of whether African American and European American elderly patients were able to participate in treatment decisions. Again, the results of the current study did not support what was expected. Ethnicity status was not a significant predictor of whether elderly patients were able to participate in treatment decisions.

A study conducted by Ladin (2018) contained participants who were recruited to take part in interviews about health literacy, end-of-life planning, and goals about personal health care. Thirty-one elderly dialysis patients participated, and the results from this study determined that 13% of patients had discussions on end-of-life with their physicians. The results highlighted that family misunderstandings, terminology for interpreting details of diagnoses, communication, and decision-making for the next of kin are challenges that ultimately lead to barriers of communication in older adults receiving inadequate information during the end-of-life discussions.

In Ladin's (2018) study, there were no noted ethnic differences in the percentage of patients who had discussed end-of-life with their physicians. Therefore, in the study, I expected that ethnicity status would not be a significant predictor of whether African American and European American had written end-of-life care instructions. The results of study supported the results of Ladin's study, as the model was unable to distinguish between African Americans and European Americans who had written end-of-life care instructions. This result revealed that that there were no discernable ethnic group differences in likelihood of having written end-of-life care instructions.

It was also expected that ethnicity status would not be a significant predictor of whether African Americans and European Americans would have documented treatment decisions in the final days of life. A nonsignificant result would indicate that the model was not able to detect any no discernable ethnic group differences in likelihood of having documented treatment decisions in the final days of life. The results of the current study supported what was expected from Ladin’s (2018) study, as ethnicity status was not a significant predictor of whether African Americans and European Americans had documented treatment decisions in the final days of life. Finally, based on the results of Ladin’s study, it was expected that ethnicity status would not be a significant predictor of whether African American and European American patients were able to participate in treatment decisions. Again, the results of the current study supported what was expected, as ethnicity status was not a significant predictor of whether elderly patients were able to participate in treatment decisions.

The health belief model purports that people are more likely to take preventative action if they believe the threat of a health risk to be serious, if they feel they are personally susceptible, and if there are fewer costs than benefits to engaging in it (Rollins, 2018). Therefore, a central aspect of the health belief model is that behavior change interventions are more effective if they address an individual’s specific perceptions about susceptibility, benefits, barriers, and self-efficacy (Jones, 2016).

Interventions focusing on this model may involve risk calculation and prediction, as well as personalized advice and education.

The health belief model does not make any ethnicity distinctions in the belief in the threat of health risks to be serious, or in the perception that fewer costs than benefits exist in taking preventive action. Therefore, I expected that ethnicity status would not be a significant predictor of whether African Americans and European Americans had written end-of-life care instructions, and this expectation was supported in the current study, as ethnicity status was not a significant predictor of whether African Americans and European Americans had written end-of-life care instructions. I also expected that ethnicity status would not be a significant predictor of whether African Americans and European Americans would have documented treatment decisions in the final days of life. This was also supported in the current study, as ethnicity status was not a significant predictor of whether African Americans and European Americans would have documented treatment decisions in the final days of life. Last, based on the health belief model, I expected that ethnicity status would not be a significant predictor of whether African American and European patients were able to participate in treatment decisions. Again, the results of the current study supported what was expected, as ethnicity status was not a significant predictor of whether elderly patients were able to participate in treatment decisions.

Limitations of the Study

There were several limitations associated with this study that adversely affect the generalizability of the study to the larger population. First, the sample was not randomly selected from the target population. As a result, the African American, European American, and Hispanic American populations in the sample were not proportionally representative of the larger population. Therefore, it is unknown whether the sample is biased in some way. Additionally, there were no Hispanic Americans contained in this sample. Therefore, no visibility exists on how this ethnic group responded to the three research questions. Another possible limitation of the study is that I relied on self-reported data (Cresswell, 2018). The respondents of this study were family members who were caregivers of the elderly who are now deceased. For example, these caregivers could have suffered from selective memory, remembering only parts of experiences and not others. Another possible issue with self-reported data is exaggeration of events. The death of a loved one is a traumatic experience, and exaggeration and selective memory are reasonable possibilities during this time.

Recommendations

The first recommendation is to collect a sample that is representative of the target population, including being representative of the ethnic makeup of the target population. The sample size was acceptable, but the representativeness of sample was weak. The second recommendation relates to data collection. Instead of focusing on only the primary caregiver or family member assisting the elderly patient, it is recommended that at least one other person close to the elderly patient be interviewed as well. Although this may require additional time and financial resources, it may increase the reliability of data by addressing possible selective memory and exaggeration of facts. The third and final recommendation is that other forms of illness be considered with collecting the sample.

This way, distinct differences can be detected in the development of written end-of-life instructions across different illness types.

Implications

The results of this study will have implications on professional practice and positive social change. Details follow on the recommendations for professional practice, and the potential impact for positive social change at the appropriate levels. Finally, I also discuss the methodological implications of this study.

Professional Practice

There were no ethnicity differences in the proportion of respondents with written end-of-life planning instructions. Additionally, the percentage of African Americans and European Americans with written end-of-life planning instructions was relatively low. Therefore, one of the implications of this study on professional practice is that leaders and health care practitioners encourage patients to have written end-of-life instructions. As a result, having end-of-life instructions are helpful for the patient and provide clear instructions on whether the patient desires to be resuscitated, receive blood work or dialysis treatment, or ventilation. In this way, the wishes of the patient are ensured.

Methodological Implications

One of the challenges of this study was that there were not enough Hispanic Americans to participate in the study. Therefore, one of the methodological implications for this study is that if, and when, this study is replicated, that there should be a sizable sampling of not only Hispanic Americans, but of Asian Americans and Native Americans as well. This is important because it is not known if or to what degree other ethnic groups have written end-of-life instructions. Without this information, there can be no determination of whether there should be an intervention to increase the proportion of people who have written end-of-life instructions in the respective ethnic groups.

Positive Social Change

Encouragement of all Americans to have written end of life instructions is important for several reasons. First, it removes the uncertainty related to the end-of-life care desires of patients. Second, it provides guidelines to health care professional on how they can effectively treat patients. Third, it documented health outcome differences among various ethnic and gender groups in the United States, even when controlling for social economic status and previous health conditions were noted. If members of these ethnic and gender groups who experience poorer health outcomes, possessed written end of life instructions, these instructions may stipulate the degree and depth of care that is expected from these patients and may, therefore, improve their health outcomes. For example, members of these poor outcome groups may be less likely to be resuscitated than members of other groups. Most important, having written end-of-life care instructions that specifically state that the patient’s desire to be resuscitated and placed on a ventilator are actions of care and, if done on a wider scale, may improve the health outcomes of patients who are at risk for poorer health and surgical outcomes, thereby having a positive effect on society.

Conclusions

Aging patients who are 55-years-of-age, and who have the ethnicity status operationalized as African American and European American, who are diagnosed as terminally ill and are at the end-of-life are highly vulnerable and need support during this phase. I expected that ethnicity status would be a significant predictor of whether patients had or did not have written end-of-life instructions. Specifically, I expected that significantly fewer African Americans would report having written end of life instructions. However, according to the current study, half of European Americans and more than half of African Americans reported that they did not have written end-of-life instructions. So, the differences between the two groups were not sizable enough to make a distinction in the model.

The results of this study benefit professional practice, future researcher, and social change. Leaders and health care practitioners should encourage patients to have written end-of-life instructions. Future studies should ensure that the sample sizes of minority groups are large enough to ensure that the results are projectable to the larger populations. Finally, if members of these ethnic and gender groups who experience poorer health outcomes possessed written end-of-life instructions, these instructions may stipulate the degree and depth of care that is expected from these patients and may, therefore, improve their health outcomes. There is a lot more that can be done to communicate the importance of end-of-life care instructions to patients.

References

African American Health. (2018, July 17). Retrieved from Centers for Disease Control and Prevention: https://www.cdc.gov/minorityhealth

Babbie, E. R. (2016). *The practice of social research* (14th ed.) [VitalSource Bookshelf version].

Bansal, A. D., & Schell, J. O. (2018). A practical guide for the care of patients with end-stage renal disease near the end of life. *Seminars in Dialysis, 31*(2), 170–177. https://doi.org/10.1111/sdi.12667

Becker, M. H. (2016). The Health Belief Model and personal health behavior. Health Education Monographs. 1974; 2:324–508

Boucher, N. A., & Care, E. (2016). Direct engagement with communities and interprofessional learning to factor culture into end-of-life health care delivery, *American Journal of Public Health, 106*(6), 996–1002. https://doi.org/10.2105/AJPH.2016.303073

Centers for Disease Control and Prevention. (2015). *Kidney Disease*. Retrieved from https://www.cdc.gov/healthcommunication/toolstemplates/entertainmented/tips/KidneyDisease.html

Centers for Disease Control and Prevention. (2017). *African American Health Creating Equal Opportunity for Health.* Retrieved from https://www.cdc.gov/vitalsigns/aahealth/#anchor_1490281920

Centers for Disease Control and Prevention. (2017). *Kidney Disease*. Retrieved from https://www.cdc.gov/nchc/fastats/kidney-disease.htm

Champion, V. L. (1999). Revised susceptibility, benefits, and barriers scale for mammography screening. *Research in Nursing and Health, 22*(4), 341–348. https://doi.org/10.1002/(SICI)1098-240X(199908)22:4<341: AID-NUR8>3.0.CO;2-P

Champion, V. L. (1984). Instrument development for Health Belief Model constructs. *ANS: Advances in Nursing Science, 6*, 73–85. https://doi.org/10.1097/00012272-198404000-00011

Champion, V. L., Skinner, C. S. (2004). Differences in perceptions of risk, benefits, and barriers by stages of mammography change. *Journal of Women's Health, 12,* 277–286. https://doi.org/10.1089/154099903321667618

Chantel Balasooriya-Smeekens, F. M. (2015). The role of emotions in time to presentation for symptoms suggestive of cancer: A systematic literature review of quantitative studies. *Psycho-Oncology*, *24*, 1594-1604. https://doi.org/10.1002/pon.3833

Chen, B., Kuo, C., Huang, N., & Fan, V. Y. (2018). Reducing costs at the end of life through provider incentives for hospice care: A retrospective cohort study. *Palliative Medicine*, *8,* 1389-1400. https://doi.org/10.1177/0269216318774899

Council, M. (2015). Patients with end-stage renal disease, *7*(6).

Creswell, J. (2018). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (4th ed.). Thousand Oaks, CA: SAGE.

Crews, D. C., Banerjee, T., Wesson, D. E., Morgenstern, H., Saran, R., Burrows, N. R., … Powe, N. R. (2018). Race/ethnicity, dietary acid load, and risk of end-stage renal disease among US adults with chronic kidney disease. *American Journal of Nephrology*, *47*(3), 174–181. https://doi.org/10.1159/000487715

Davison, S. N., Holley, J. L., & Seymour, J. (2011). Advance care planning in patients with end-stage renal disease. *Supportive Care for the Renal Patient*, *17*(4). https://doi.org/10.1093/acprof:oso/9780199560035.003.0005

Death, E. (2019). Chronic kidney disease in the United States. National chronic kidney disease facts. Retrieved from Centers for Disease Control and Prevention: https://www.cdc.gov/nchc/fastats/jidney-disease.htm

Eneanya, N. D., Goff, S. L., Martinez, T., Gutierrez, N., Klingensmith, J., Griffith, J. L., … Cohen, L. M. (2015). Shared decision-making in end-stage renal disease: A protocol for a multi-center study of a communication intervention to improve end-of-life care for dialysis patients. *BMC Palliative Care, 14*(1), 1–8. https://doi.org/10.1186/s12904-015-0027-x

Frahm, K. A., Barnett, S. D., & Brown, L. M. (2011). Trends in hospice utilization across age among veteran population. *American Journal of Hospice & Palliative Medicine, 28*(6), 424-428. doi:10.11.77/1049909110397655

Fulghum, J. (2014). Utilizing the Health Belief Model to Assess Vaccine Acceptance of Patients on Hemodialysis, *41*(4), 393–408.

GCHM. (2015). Leadership Competencies for Healthcare Services Managers. *International Hospital Federation*, 1–12. Retrieved from file:///C:/Users/User/Desktop/nickmwenda/SBS/Research/Leadership_Competencies_Healthcare_Services_Managers.pdf

Grant, M. (2017). Understanding Cultural Gaps and Disparities in Advanced Illness Care, *41*(1), 10–16.

Griffin, M. J. (2012). Health belief model, social support, and intention to screen for colorectal cancer in older African American men. *Health Promotion & Education, 51*(1), 12–22.

Harding, K., Mersha, T. B., Webb, F. J., Vassalotti, J. A., & Nicholas, S. B. (2017). Current State and Future Trends to Optimize the Care of African Americans with End-Stage Renal Disease. *American Journal of Nephrology*, *46*(2), 156–164. https://doi.org/10.1159/000479479

Hayes, J. A. (2012). *PROCESS: A versatile computational tool for observed variable mediation, moderation, and conditional process modeling* [White paper]. Retrieved from http://www.afhayes.com/public/process2012.pdf

Hussain, J. A., Flemming, K., Murtagh, F. E. M., & Johnson, M. J. (2015). Patient and Health Care Professional Decision-Making to Commence and Withdraw from Renal Dialysis: A Systematic Review of Qualitative Research. *CJSASN Clinical Jornal of American Society of Nephrology*, *10*(7), 1201-1215. https://doi.org/10.2215/CJN.11091114

HRS The Health and Retirement Study. (2018). Retrieved from The Health and Retirement Study: hrsonline.isr.umich.edu

Illness, A., & Care, E. (2017). Next-Generation Quality Measurement to Support Improvement in, *41*(1), 86–94.

Jade Odgers, D. F. (2012 to 2013, January to June). No one said he was dying: families' experiences of end-of-life care in an acute setting. *Australian Journal of Advanced Nursing*, 21-31.

Joint Commission’s video highlights patient rights. (2012). *Same-Day Surgery,* 4. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=shib&db=ccm&AN=79193491&site=eds-live

Jones, C. L., Jensen, J. D., Scherr, C. L., Brown, N. R., Christy, K., & Weaver, J. (2016). HHS Public Access, *30*(6), 566–576. https://doi.org/10.1080/10410236.2013.873363.The

Juster FT, Suzman R. An overview of the Health and Retirement Study. J Hum Resource 1995; 30: S7eS56.

Kelley, A. T., & Doolittle, B. (2018). Barriers to Advance Care Planning in End-Stage Renal Disease: Who is to Blame, and What Can be 24(2), 150–157. https://doi.org/10.1080/20502877.2018.1438772

Ladin, K., Buttafarro, K., Hahn, E., Koch-Weser, S., & Weiner, D. E. (2018). "end-of-Life Care? I'm not Going to Worry About That Yet.” Health Literacy Gaps and End-of-Life Planning among Elderly Dialysis Patients. *Gerontologist*, *58*(2), 290–299. https://doi.org/10.1093/geront/gnw267

Marti-Garcia, C., Garcia-Caro, M. P., Cruz-Quintana, Francisco, Schmidt-RioValle, Jacqueline, and Perez-Garcia, Miguel. (2016, February). Omega. *Journal of Death & Dying, 72*(3), 191-209.

Mattes, M., Tung, K., & Baum, R., Parikh, and Ashamalla, Hani (2015, December).

Understanding the views of those who care for patients with cancer on advance care planning and end of lie care. *American Journal of Hospice and Palliative Medicine*, *32*(8), 802-809.

Merriam, G. a. (1991). *Merriam Webster Dictionary*. Springfield, MA: Webster Publish.

Morgan, D. L. (2014). Pragmatism as a paradigm for social research. *Qualitative Inquiry*, 20(9), 1045-1053.

National Center for Health Statistics. (2018, June 22). Retrieved from Centers for Disease Control and Prevention: https://www.cdc.gov/nchs/data_access/ftp_data.htm

NHPCO. (2015). NHPCO's Facts and Figures: Hospice Care in America. National Hospice and Palliative Care Organization. Retrieved from http://www.Pallimed.org/2015/09/nhpco-release-2015-facts-and-figures.html

Novelli, B. B., & Banerjee, R. (2015). Advanced Illness Care: We Can Do Better, *39*(2), 106–112.

Ormrod, P. D. (2018). Practical Research: Planning and Design. In P. D. Ormrod, *Practical Research: Planning and Design* (p. 441). Pearson College, Div.

Patti L Ephraim, N. R.-B. (2012). The providing resources to enhance African American patients' readiness to make decisions about kidney disease (PREPARED) study: Protocol of a randomized controlled trial. *BMC Nephrology*, 13-135.

Phillips, C. R., MacNab, C. J., & Loewen, L. M. (2018). Advanced Care Planning and Chronic Kidney Disease: What Do Patients Know and What Do They Want? *American Nephrology Nurses Association*, *45*(6), 513-523.

Policy statement: Decisions near the end of life. (2011). *Frontiers of Health Services*

Management, 27(3), 49-51. Retrieved from https://search.proquest.com/docview/863740879?accountid=35812

Queeley, G. L., & Campbell, E. S. (2018). Comparing treatment modalities for end-stage renal disease: A meta-analysis. *American Health and Drug Benefits, 11*(3), 118–125. https://doi.org/10.1016/j.jval.2014.03.1690

Rollins, L., Id, A. S., Crowell, N., Rivers, D., Id, A. M., Cooper, P., … Ofili, E. (n.d.). Learning and Action in Community Health: Using the Health Belief Model to Assess and Educate African American Community Residents about Participation in Clinical Research, 1–15. https://doi.org/10.3390/ijerph15091862

Rosenstock IM. Historical origins of the health belief model. Health Education Monographs. 1974; 2:328–335.10.1177/109019817400200403

Scarinci I, Bandura L, Hidalgo B, Cherrington A. Development of a theory-based, culturally relevant intervention on cervical cancer prevention among Latina immigrants using intervention mapping. Health Promotion Practice. 2012; 13:29–40.10.1177/1524839910366416 [PubMed: 2142

Smith-Howell, E. R., Hickman, S. E., & Meghani, S. H. (2016). End-of-Life Decision Making and Communication of Bereaved Family Members of African Americans, *19*(2), 174–183. https://doi.org/10.1089/jpm.2015.0314

The Health and Retirement Study sample sizes and response rates 2011. Available from http://hrsonline.isr. umich.edu/sitedocs/sampleresponse.pdf. Accessed October 1, 2019.

van de Riet, M. C. P., Berghout, M. A., Buljac-Samardzic, M., van Exel, J., & Hilders, C.

G. J. M. (2019). What makes an ideal hospital-based medical leader? Three views of healthcare professionals and managers: A case study. *PLoS ONE*, (6). Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=shib&db=edsgov&AN=edsgcl.588587494&site=eds-live

Wachterman, M. W., Lipsitz, S. R., Lorenz, K. A., Marcantonio, E. R., Li, Z., & Keating, N. L. (2017). End-of-Life Experience of Older Adults Dying of End-Stage Renal Disease: A Comparison with Cancer. *Journal of Pain and Symptom Management*, *54*(6), 789–797. https://doi.org/10.1016/j.jpainsymman.2017.08.013

Washington, K. T., Oliver, D. P., Gage, L. A., Albright, D. L., & Demiris, G. (2016). A multimethod analysis of shared decision-making in hospice interdisciplinary team meetings, including family caregivers. https://doi.org/10.1177/0269216315601545

Weissman, D. E. (2000). New End-of-Life Guidelines. *Journal of Palliative Medicine*, *3*(2), 149–150. https://doi.org/10.1089/10966210050085205

Wicher, C. P., & Meeker, M. A. (2012). Part 1: Literature review what influences African American end-of-life Preferences? *Journal of Health Care for the Poor and Underserved*, *23*, 28–58.