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The Underuse of Hospice Care in the African American Military Beneficiary Population

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Abstract

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Abstract

Hospice services provide a holistic approach to end-of-life care to terminally ill patients though there is some evidence to suggest that African American military beneficiary populations may not access hospice care as often as expected. The purpose of this nonexperimental study was to evaluate reasons for the low use of hospice care among the terminally diagnosed members of this population, between the ages of 18 and 64. Kolcaba's comfort theory provided the theoretical framework for this study. The research explored whether a statistically significant difference exist among African Americans military beneficiaries population as compared to non-Hispanic Whites pertaining to their knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans. This study used a simple random sample of 32 participants (18 African Americans and14 non-Hispanic White) from a military ambulatory care setting in Maryland. Johnson, Kuchibhatla, and Tulsky's End-of-Life Care survey was used to collect data from the 2 groups of participants. Data were analyzed using a one-way multivariate analysis of variance. The results indicate that there are not statistically significant differences between the groups in terms of knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans based on race. Based on the results of this study, further research is recommended to replicate using a larger sample size to include other minority groups at more than one medical treatment facility. The implication of this study may open up an avenue to policy makers and administrators who are responsible for disseminating information about hospice benefits to focus on improving the quality of the end-of-life for terminally ill patients.

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Dedication

I would like to dedicate this dissertation to my husband, Jasper Jr., and my beautiful daughter, Sierra Denise, who have been my rock and source of inspiration and encouragement throughout this entire process. Thanks to my brothers: Gartreal, Dennis Sr., and LaVal Sr.; and my family Cynthia and nieces who were always there providing their unwavering support and patience with me when I was not able to come home because of military duties or other commitments. I also dedicate this dissertation to the memory of my beloved mother, Mrs. Ella Mae Castleberry (1926-2014), for being such a God-fearing women and exemplifying the essence of education, telling me the “the sky is the limit,” and “you can do anything you want as long as you put your mind to it and just trust in the Lord.”

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Chapter 1: Introduction to the Study

Many individuals who feared to seek services from a hospice agency once knew hospice care and awareness as a taboo. In 2014, the National Hospice and Palliative Care Organization (NHPCO, 2015) estimated that approximately 1.6 to 1.7 million patients in the United States received some type of services from hospice care. Of that number, African Americans accounted for 7.6% in 2014 as compared to 76.0% in the non-African Americans (Table 1).

Table 1

Percentages of Hospice Patients by Ethnicity

Patient Race	2013	2014
Non-African American (Caucasian)	80.9%	76.0%
African American	8.4%	7.6%

Note. Adapted from “NHPCO Facts and Figures: Hospice Care in America,” by the *National Hospice and Palliative Care Organization*, September 2015, p.7.

The decrease among the African American population from 2013 to 2014 could be a different in the use of hospice care in this population. The purpose of this study was to determine factors that contribute to the low underuse of hospice service in African American military beneficiary population who had accepted the diagnosis of a life-limiting illness and may have fewer than 6 months to live.

Cultural differences and beliefs about death and dying can have an influence on health care use. It is important to explore if these factors would have an impact on the use of hospice care in the African American military beneficiary population group ages 18-64. A number of studies have been conducted on the barriers and or factors among the African Americans and non-African Americans for the underuse of hospice care, as well as veterans in the age group of 65 and older. However, there has been no research conducted on military beneficiary in this age group, a gap that I attempted to fill.

Encouraging and offering hospice services to the African American military beneficiary population group in the beginning stage of their life-limiting illness will reduce the fear of dying alone and will help to maintain dignity at the end of life (Tang, French, Cipher, & Rastogi, 2012). The results of this study would be beneficial in providing information to public administrators who could help reduce the Department of Defense (DoD) budget during budget constraints when resources are needed to provide services to an increasing number of military beneficiaries. The results of this study can be used to raise awareness about the knowledge of hospice care, not only for the facility, but also for the entire population that is diagnosed with a type of life-limiting illness. The patients, physicians, and family members would have the opportunity to maximize the benefits that are offered by hospice services. The background, problem statement, purpose of the study, research questions and hypotheses, theoretical framework, nature of the study, definitions, assumptions, limitations, and significance discussed in this chapter.

Background

Hospice was first referenced back in the 4th century in the port of Rome. It was noted by a disciple of Saint Jerome named Fabiola who was taking care of pilgrims who were returning from Africa (Tang et al., 2012). Hospice care and awareness was known as taboo because many individuals feared death and the association of suffering and loneliness that often accompanies death. This phenomenon led to the first hospice movement in 1970s in the United States by Kubler-Ross and Wald (Hoffmann, 2005). These two visionaries recognized this fear and launched new concepts of patient care for those who were dying.

Death and dying can be a difficult concept for patients and families to discuss, especially when a loved one has been diagnosed with a terminal illness. Death and dying concepts produced a paradigm shift in the delivery of care from a cure model to a comfort model (Hoffmann, 2005). Vendlinski & Kolcaba (1997) introduced the comfort model in the 1990s to nursing institutions and hospice nursing as a framework for assessing comfort and planning interventions that would provide the comfort of patients and their families. The goal of hospice is to ensure that the patient remains pain free and as comfortable as possible without diminished the patient sensorium during the final stages of life.

Hospice uses two basic models: a community-based model as free standing units or offices and an institutional-based model as a discrete unit within an acute care facility (Hoffmann, 2005). In the late 1980s, the National Hospice Organization organized the American Academy of Hospice and Palliative Medicine. In 2000, the name was changed to the National Hospice and Palliative Care Organization (NHPCO) to accommodate both hospice and palliative care patients. The focus of this union was to have a compassionate care model for individuals who are facing life limiting illness and challenges. This model consists of an interdisciplinary team who can provide expert medical care, pain management, bereavement care, emotional, psychosocial, and spiritual support that will be tailored to patient needs and wishes, as well as their love ones (NHPCO, 2015). The main goal of hospice is to focus on caring and not curing. It is available to anyone of all ages with terminal illness, despite race, religion, or creed.

There are barriers that have been consistently identified with the underuse of hospice care in the older African American population. Despite all of the researchers who have identified the underuse of hospice care in African American population, the age group that have been rarely studied are the military beneficiaries ages 18 to 64. Frahm, Barnett, and Brown (2011) noted that veterans in the age group 65 and older accounted for approximately 40% of the total veteran population (9,166,281 individuals), which is expected to increase in growth by 2020. As a result, nearly all studies of veterans and hospice use rate in the African American population have been concentrated in the older veterans. The factors among the younger veteran that contribute to hospice underuse are still unknown. Based on the lack of literature on the factors that contributes to the underuse of hospices among the African American veterans population among age group of 18-64, this research will provide an opportunity to contribute to this body of knowledge from the literature to bring about a positive social change in the military treatment facilities (MTFs).

Problem Statement

The African American military beneficiaries who are facing some life limiting illnesses have a low use rate of hospices. These patients have a choice to use hospice care for them to receive a comfortable and dignified end-of-life (EOL) experience (NHPCO, 2015).

Despite numerous services of hospice care readily available for individuals who are experiencing life limiting illnesses, the use rate remains low in the military beneficiaries' population. The low use of hospices prevents the African American military beneficiaries aged 18-64 who are facing life limiting illnesses in MTFs from benefitting from the support that hospice provides (Connor, Elwert, Spence, & Christkis, 2008; Dussen, Culler, & Cagle, 2011). The following could be causes for the low use of hospice care among African American beneficiaries: (a) the lack of knowledge about the program, (b) cultural differences, (c) attitudes and beliefs about hospice, and (d) mistrust of health care personnel (Carrion, Park, & Lee, 2012; Johnson, Kuchihatla, & Tulsky, 2008; Ruff, Jacobs, Fernandez, Bowen, & Gerber, 2011). A study to identify factors such as lack of knowledge about hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans by a quantitative approach could remedy the low use of hospice care among African American population.

Several researchers have identified the low underuse of hospice care in the African American population, but the age group rarely included military beneficiaries ages 18 to 64 (Carrion et al., 2012; Frahm et al., 2011; Johnson et al., 2008; Manu et al., 2012). In order to understand the low use rate of hospice care among the African American military beneficiary ages 18-64, it was necessary to identify factors as stated earlier. I used a quantitative, cross-sectional, correlational, descriptive, nonexperimental design to test the dependent variables of the lack of knowledge about hospice, attitudes and beliefs about hospice care, advanced care planning, and mistrust of health care personnel as factors that contributed to the reason or reasons for the lack of use of hospice care among the African American military beneficiary population in the age group of 18-64.

Purpose of the Study

This quantitative study served two purposes. The first purpose was to determine the reason or reasons for the low use of hospice care in the African American military beneficiary population in the age group of 18-64 in the United States. The second purpose was to promote more effective educational and informational programs through distributing brochures, poster presentations, and annual hospice awareness in-service training. This study provided insight not only on the African American military beneficiary population, but provided information on other ethnic group's use of hospice care.

Research Question and Hypotheses

This study was guided by a research question that had associated hypotheses. The hypotheses were stated in null and alternative form. Multivariate analysis of variance (MANOVA) was used to test the difference between dependent variables. As noted by Field (2009), a MANOVA is used if there were several dependent variables involved to be measured.

Research Question 1: Is there a statistically significant difference among African American military beneficiary population ages 18-64 as compared to other groups related to their knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans?

$H_0$1a: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to the lack of knowledge about hospice care.

H_a1a: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to the lack of knowledge about hospice care.

$H_0$1b: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to attitudes and beliefs about hospice.

H_a1b: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to attitudes and beliefs about hospice.

$H_0$1c: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to distrust in the health care system.

H_a1c: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to distrust in the health care system.

$H_0$1d: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to advanced care plans.

H_a1d: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to advanced care plans.

Theoretical Framework

This study was based on the comfort theory (CT), first developed by Kolcaba in 1997. Making EOL decisions can be difficult for the patients and family members, and the family may struggle to find a sense or degree of comfort during these expected and/or unexpected times. A theoretical framework that can be applied to all facets of health care and management is the CT. The CT is congruent with the hospice philosophy of meeting the comfort needs of the patient and providing an environment for a peaceful death. Kolcaba et al. (2006) noted that when patients and family members are more engaged and involved with decision making and health seeking behaviors, the quality of care and satisfaction for patients and family members are increased. The use of this theory may assist African American military beneficiary in the age group of 18-64 with decision making as it relates to knowledge about hospice care, attitudes and beliefs about hospice, mistrust in the health care system, and advanced care plan decisions. Chapter 2 of this study includes a detailed discussion about the CT.

Nature of the Study

The nature of this study was a quantitative, cross-sectional, correlational, descriptive, nonexperimental design. The quantitative research design was an appropriate methodology for this study to explore objectives that used a systematic strategy for generating and refining knowledge. The primary focus of a quantitative study is based on deductive reasoning and generalization (Sousa, Driessnack, & Mendes, 2007). Hopkins (2000) posited that a quantitative research used descriptive or experimental that determined the relationship between an independent variable and dependent variable in a population. In this study, the independent variable was African American race, which was used to predict lack of knowledge, attitudes and beliefs, mistrust of the healthcare personnel, and advanced care plans, the dependent variables. A modified Hospice Values and Barriers Scales, Healthcare System Distrust Scale, and the EOL care survey developed by Johnson, Kuchibhatla, and Tulskey (2008) was used to predict factors that contributed to the underuse of hospice care among the African American military beneficiary population in the age group of 18-64. The study involved two groups: African American and European American, non-Hispanic military beneficiary in the age category of 18-64. Other designs were taken into consideration such as qualitative research design. Maxwell (2005) posited that qualitative study is more of a process rather than an outcome. As a result of this study, the research focused on exploring factors that prevented the African American beneficiary population, who had been diagnosed and accepted a life-limiting illness from utilizing hospice service.

Definitions

Beliefs about dying and advance care planning: This scale included seven statements exploring beliefs about the inevitability of death and comfort discussing death (Johnson et al., 2008).

Culture: A term that incorporates concepts of race, ethnicity, religion, language, national origin, and other factors (Bullock, 2012).

Durable power of attorney (DPOA): A DPOA for Health Care or a Health Care Power of Attorney is a written document naming a person to make medical decisions for a person if that person is unable to make their own decisions (Johnson et al., 2008).

Emotional burden: A residual negative feelings and concerns family members have when they think about their loved one’s death and the decision making surrounding it (Radwany et al., 2008).

End-of-life (EOL) decision making: An integral component of quality health care, specifically in decisions about initiating, withholding, or withdrawing life sustaining treatments (Ache et al., 2011).

Ethnicity: A maker for cultural beliefs and values that may influence EOL decision making (Bullock, 2012).

Hospice attitudes and beliefs: This scale includes eight statements examining attitudes toward hospice care, including desire for hospice care and beliefs about the care that hospice provides (Johnson et al., 2008).

Hospice care: A program that provides care to people with illnesses that cannot be cured when they are at the end of their lives (Johnson et al., 2009).

Mistrust in health care system: Referred to as the belief that health care in the United States is driven by powerful economic and societal forces rather than the best interests of the patient (Washington, Bickel-Swenson, & Stephens, 2008).

Palliative care: An all-encompassing approach to cancer care that focuses not only on symptom control, but on other aspects of life important to patients and families in an attempt to prevent and/or alleviate suffering (Keyser et al., 2010).

Preferences for EOL care: This scale includes eight statements exploring beliefs about the desire to live as long as possible with a terminal illness even if on life support, brain dead, receiving nutrition through a tube, or in severe pain (Johnson et al., 2008).

Quality of life (QOL): An individual's perception of his or her position in life in the context of the culture and value system in which he or she lives and in relation to his or her goals, expectations, standards, and concerns (White, 2013).

Assumptions

The first assumptions of this study were that the participants volunteered to participate and that the questionnaires were answered honestly and their responses did not bias the study results. It was further assumed that the study instruments for data collection were valid and reliable based on previous use in hospice research. It was assumed that the modified Hospice Values and Barriers Scales, Healthcare System Distrust Scale, and End-of-Life care survey was appropriate for determining factors that contribute to the underuse of hospice care of the study participants. The final assumptions were that the participants would have access to the computer and Internet at the facility and that they would be able to complete an online survey independently or with assistance, voluntarily and in its entirety.

Scope and Delimitations

I explored factors that contributed to the underuse of hospice care in the African American military beneficiary population in the age group of 18-64. This population was men and women who accepted their diagnosis of a terminal illness and received their primary care or were hospitalized at Walter Reed National Military Medical Center Bethesda (WRNMMCB). According to Tang et al. (2012), minorities in general will have more barriers to hospice care than the non-African Americans.

Not all of the factors about the underuse of hospice care were discussed in this study. Some of the factors that would have had some influence on the underuse of hospice care in the African American military beneficiaries population were a lack of diversity in hospice teams, religious beliefs, hospital admission criteria, and insurance (Tang et al., 2012). A simple random sampling was drawn from a military setting hospital oncology, neurology, dialysis, and medical units and or clinics from WRNNMCB that could have an effect on external validity. According to Frankfort-Nachmias and Nachmias (2008), “randomization contributes to the internal validity of the study, it does not necessarily ensure that the sample is representative of the population of interest” (p.101). According to Creswell (2009), future scholars should focused on exploring all race and ethnic backgrounds and a study should be replicated to determine if the same results would occur.

Limitations

The first limitation of this study was only one minority group in the age group of 18-64 was sampled. The results of this study applied to other minority groups such as Hispanic

Americans, Native Americans, and Asian Americans/Pacific Islanders who need to be studied in the future. The sample size was small, and it limited my ability to uncover if there were significant differences in the low use of hospice care among the African American military beneficiary populations in the age group of 18-64. However, I focused on the lack of knowledge about hospice, attitudes and beliefs about hospice, preference for care, advanced care planning, and mistrust of the health care system in the African American military beneficiary populations in the age group of 18-64. Another limitation of this study was that all of the participants were from one military facility; no other military facilities and or nursing homes were used, and the results may not be generalizable to other populations of veterans/beneficiaries.

The final limitation of this study was spirituality. It was not assessed, which may be a factor that influenced the underuse of hospice care in the African American military beneficiary populations. White (2013) noted that spirituality plays provides a positive outlook of peacefulness, reasons for living, a sense of purpose and a sense of harmony to individuals who have chronic health problems. Future researchers should explore spirituality as a factor regarding the use of hospice care among the African American military beneficiaries population.

Significance

Despite the research in the African American military veteran population on factors that contribute to the underuse of hospice care among older adults, there has been little research in the age group of 18-64. Scholars have not studied age as a factor that may lead to the underuse of hospices in the African American veteran population (Fraham et al., 2011). The key is to have a better understanding of the factors that will make a difference when it comes to QOL in this group of military beneficiaries. I addressed the gap by analyzing attitudes and beliefs about hospice care, a lack of knowledge about hospice care, preference for care and advanced care planning, and mistrust of the health care system in the African American military beneficiaries' population in the age group of 18-64 who were diagnosed and accepted their terminal illness. Positive social change implications for this study included recommendations to the military policy makers and administrators in health services to focus on improving the quality of the EOL for the terminally ill patients by having knowledge that will useful when making a decision about the use of hospice care. This study would have an impact in the field of public administration because it can improve current practices and protocols for the terminally ill patients throughout the military treatment facility.

Summary

The word hospice has been known to many as a taboo. It is associated with a feeling of loneliness and death. The phenomenon of death and dying can be a difficult concept for patients and families to discuss when faced with the EOL decisions. The purpose of this study was to determine factors that contribute to the underuse of hospice care in the African American military beneficiary population in the age group of 18-64. Although, the African American military beneficiary population has not been adequately studied, it is importance for an individual and family to have optimal QOL. In order to accomplish this, many health care facilities are utilizing the CT. The goal of the CT is to meet the comfort needs of an individual while providing them with an environment for a peaceful death. The nature of this study was quantitative research design that was based on deductive reasoning and generalization. The study was based on a modified Hospice Values and Barriers Scales, Healthcare System Distrust Scale, and End-of-Life Care Survey developed by Johnson et al. (2008). The survey was used to predict differences in cultural beliefs and values as they relate to factors that had an influence on EOL decisions and hospice use.

The research question addressed the effect on the lack of knowledge about hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans as a result of African American military beneficiary population ages 18-64 not using hospice care to its fullest extent. The African American is a population that not enough information has been studied about factors that may lead to the underuse of hospice care (Fraham et al., 2011). The implication of social change is to recommend to higher military authority to implement a policy that would focus on improving the quality of the EOL for terminally ill patients. By empowering these patients and their families to make an informed decision about hospice care. Chapter 2 is a review of the relevant literature review on barriers and factors that contribute to the underuse of hospice care in the African Americans military beneficiary population.

Chapter 2: Literature Review

Introduction

This chapter is a review of the relevant literature on barriers and factors related to the use of hospice care among the African American military beneficiaries' population aged 18-64. I explored this population and age group to determine why they would not use hospice care at the same rate as the non-African American population. WRNMMC and Walden University Libraries databases were the principal source for the literature search. Databases and articles not readily accessible were requested through the interlibrary loan service at WRNMMC. The following databases were searched: Academic Search Premier, Dissertation and Thesis ProQuest, Educational Resource Information Center (ERIC), Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and Medline. The following key words were used for this literature review search: *ages18 to 64 African Americans and Caucasian Americans, veterans, hospice, barriers and factors, African Americans and hospice, hospice utilization in minorities, hospice utilization in African Americans/Blacks, end-of-life care, racial disparity, palliative care, advance directives, cultural mistrust,* and *hospice access.* I identified 248 relevant references on pertinent information related to a lack of knowledge, attitude, beliefs, advanced care planning, veterans, and cultural influences as barriers or factors that contribute to the underuse of hospice care in the African American population. Forty-six references were used in this study.

Theoretical Foundation

This study was based on the CT, first developed by Vendlinski & Kolcab (1997). The CT was first known as the patient/family-centered theory. Novak, Kolcaba, Steiner, and Dowd (2001) defined the CT as “the immediate experience of being strengthened by having the need for three type of comfort (relief, ease, or renewal) met in four contexts of human experience (physical, psychospiritual, environmental, and social)” (p.171). The CT is congruent with the hospice philosophy of meeting the comfort needs of the patient and providing an environment for a peaceful death. The CT is centered on the strengthening aspect of comfort. There are three types of comfort that guides this theory. The first type of comfort is relief, and this type of comfort occurs when an individual’s needs have been met. The next type of comfort is ease where an individual is calm and content. The last type of comfort is renewal or transcendence where an individual can rise above his or her problems or pain. Kolcaba’s CT has been adopted at the institutional level to provide the framework for nurses to work with patients and families as they prepare for the moment of dying and death (Whitehead, Anderson, Redican, & Stratton, 2010).

Comfort is not a new phenomenon to the practice of hospice care and the health care arena. Kolcaba’s CT was introduced to hospice nursing as a framework for assessing comfort and designing interventions that would enhance the comfort of patients and their families (Vendlinski & Kolcaba, 1997). The CT is important to hospice care nurses because it provides a cohesive and rational approach for every aspect of care. It also provides a guide to individualizing the holistic approach of comfort care that is consistent with taking care of the dying patients and their families.

The main goal of the CT is to keep an individual at a level where he or she can be more relaxed and calm and not focusing on the discomfort of his or her pain. Kolcaba, Dowd, Steiner, and Mitzel (2004) used the CT in an experimental study to test the efficacy of using hand massage to enhance the comfort of hospice patients. Kolcaba et al. posited that the overall goal of hospice care is to focus on the needs of the patient during the dying process coupled with holistic interventions that addresses the physical, psychospiritual, sociocultural, and environmental needs of the patient and family. Adopting the CT in hospice patients and using hand massage brought about calmness in them and showed an improvement in physical symptoms, such as reduction in pulse and respiration rates and pain intensity. Kolcaba et al. noted that when patients and family members are more engaged and involved with decision making and health seeking behaviors, the quality of care and satisfaction for patients and family members are increased.

I chose the CT theory because it is used in the health care arena as well as in hospitals setting, and the uniqueness of my study population and age group that would benefit from the health care staff using Kolcaba’s CT framework to provide comfort care to their patients and families. Vendlinski and Kolcaba (1997), indicated, “the frame for comfort care offers a theory-based foundation upon which to build patterned, individualized methods for the practice of comforting, the essence of hospice nursing” (p.275). This theory will afford the patient and family members the ability to concentrate on the individual QOL that will make transitioning to the next phase to be as smooth as possible.

Overview of the Problem

Despite all of the researchers who have identified the underuse of hospice care in African American population, the age group that is rarely included in studies is the military beneficiaries ages 18-64. This age group and the factors that contribute to the hospice underuse of the African American veterans population has not been adequately studied (Frahm et al., 2011). Frahm et al. noted that veterans in the age group of 65 and older accounted for approximately 40% of the total veteran population (9,166,281 individuals), which is expected to increase in growth by 2020. As a result, nearly all studies of veterans and hospice use in the African American population have been concentrated on the older veterans, and little is known about the desires and wishes of the younger veterans. It is imperative to gain a better understanding of the factors that have an impact on the quality of the EOL and prevent this age group from using hospice services.

The main goal of hospice is to decrease an individual’s fear of dying alone and to make them as comfortable as possible as they are transitioning to the finality of life. Hospice and EOL care have become a growing area in the military veteran’s population. As the military beneficiaries’ population gets older, it is important to address the optimization of EOL care with younger military veterans who have been diagnosed with terminal illnesses. I explored the contributing factors that would prevent this age group from using hospice care.

Literature Review Related to Factors and Barriers

According to the NHPCO (2015), approximately 1.6 to 1.7 million patients received some form of services from hospice. Hospice providers ensure that patients who are in their final stage of life and getting ready to make that transition is done in a natural, dignified, and pain free manner. Washington et al. (2008) conducted a systematic review on barriers to hospice care among African Americans. The NHPCO identified barriers such as personal or cultural values in conflict with hospice philosophy, a lack of awareness of hospice services, concern about burdening family, economic factors, mistrust of the health care system, and an expected lack of ethnic minority employees in hospice agencies. The mistrust of health care providers was substantial barrier, and concern about burdening family and financial concern were significant barriers. These are concerns when it comes to African American employing the use of hospice services. Their participants were older African Americans in the age groups 65 and over, and limited information is known about the military beneficiaries' population age group 18-64, which makes this study different from previous studies.

Attitudes and beliefs about hospice care also contribute to the underuse of hospice services in the older African American populations. Ache, Shannon, Heckman, Diehl, and Willis (2011) compared attitudes toward hospice referral between African American and European American primary care providers (PCPs). Ache et al. used a 17 question survey tool that was developed by PCPs at the Mayo Clinic Florida. Sixteen of 17 questions consisted of attitudes toward hospice referral, and one question referenced the physicians' personal experience with hospice. Ache et al. studied 167 European

American physicians and 46 African American physicians. Ache et al. indicated that there were statistically significant differences in attitudes toward hospice between African American and European American physicians and that these differences could be attributed to the patient race rather than physician race.

In an effort to identify why African Americans consistently underused hospice services, Carrion, Park, and Lee (2012) conducted a quantitative study to ascertain the pattern of hospice services as they relates to the different racial and ethnic groups in the Central Florida region from August 2002-August 2006. Carrion et al. used chi-square and ANOVA tests to examine "the association between the characteristics of hospice user and race/ethnicity of 22,936 participants (80.6% White, 9.6% African Americans, 9.3% Hispanic, and 0.5% Asian American/Pacific Islander)" (p. 116). Carrion et al. revealed that race/ethnicity was significantly associated with all user characteristics (p<.01), and those of who died in the hospice setting, their length of stay was not significantly different across the four groups (p>.05). African Americans and Asian American patients with a diagnosis of advanced cancer are less likely than European Americans to enroll in hospice. Other researchers have suggested that African Americans and other minorities consistently underuse hospice services despite its benefits due to a lack of trust in the conventional medical care, difficult with navigating and accessing the medical system, and the lack of providers that are culturally competent (Ache et al., 2011). The research I conducted is different because it focused on the factors that contribute to the underuse of hospice care among the African American population but looking at a unique population and age group.

Manu et al. (2012) posited that elderly adults had a better appreciation for perceptions and attitudes about hospice and palliative care. Manu et al. surveyed 187 community dwelling older adults using a cross-sectional descriptive study about familiarity, perceptions, and attitudes toward hospice and palliative care. Manu et al. suggested that elderly patients who had familiarity with the term palliative care also had better attitudes towards EOL care. Although this review does not impact the underuse of hospice care or service with any particular ethnic groups, it state that more education is needed among the elderly population. It is important to determine from the research study I conducted if the younger population in the age group 18-64 of military beneficiaries shares the same perceptions and attitudes about hospice and EOL care as the older population in the age group 65 and over.

Hospice and Attitudes, Cultural Beliefs, and Values

Cultural beliefs and attitudes have played a major role among the African Americans population when it comes to enrolling into hospice care. Johnson et al. (2008) identified cultural beliefs and values as factors that would account for differences between African Americans and European Americans when it comes to the use of advance directives and hospice beliefs care. Johnson et al. based their study on five scales: the Hospice Beliefs and Attitudes, Preference for Care, Spirituality, Healthcare System Distrust, and Beliefs about Dying and Advance Care Planning. The study consisted of a cross-sectional survey of African American and European American adults aged 65 or older. Johnson et al. concluded that African Americans are less likely than European Americans to have favorable beliefs and attitudes about hospice and are less likely to have an advance directive. There is little evidence in the literature review among the younger adult population and the young military beneficiary population and their beliefs and attitudes towards hospice, as well as the use of advance directives.

Ruff et al. (2011) studied how prior knowledge of advance directives, living wills, and hospice services among all ethnic groups have been associated with favorable attitudes towards hospice services. Ruff et al.'s sample consisted of 331 South Floridians with ages that ranged from 18 to 84 years. Ruff et al. concluded that individuals who have prior knowledge of living wills, advance directives, hospice services, and higher level of education will have positive attitudes toward hospice care. Prior knowledge of these factors will lead to limited medical intervention preference at EOL, and individuals will be more comfortable communicating about issues when it comes to death and dying. Patient education on EOL care in all patient care settings, whether it is inpatient or ambulatory, will increase hospice use and will minimalize the underuse of hospice care in the minority populations. The purpose of my study was to determine younger military beneficiaries' ages 18-64, prior knowledge of hospice services and advance directives.

Dussen, Culler, and Cagle (2011) indicated that the lack of knowledge and attitudes about hospice care and EOL issues are reasons why hospice services goes underused among the African American population and other minority groups. The study was based on 148 adults aged 43 and older in Ohio using a referral-base sampling strategy about attitudes, perceptions, and knowledge about hospice. Dussen et al. suggested that improving public awareness of hospice and its services could improve access to care and reduce the disparities in EOL care. This study consisted of military veterans in the age group 18-64 at a local military treatment facility in the Maryland area, which was unique due to the age, gender, and location that different the general populace.

Hospice and Racial Disparity

Racial disparity may have played a role in the underuse of hospice care in the African American population. Connor et al. (2008) explored the possibility of racial disparity as a factor of hospice use in the African American population due to the increase growth of hospice in the Unites States, which may have impacted the access to hospice by all racial groups. Connor et al. posited that minorities are more likely to die in the hospital than European Americans, and they used hospice services at a lower rate. Connor et al. studied African American and European American decedents in the United States by sex, age, place of residence, and cause of death using a comprehensive, national level data from population registries and Medicare claims records for the year of 2002. The focus was on Medicare-based hospice use 12 months before death in the stated population of individuals who died in 2002. Connor et al. found that the racial disparity in the use of hospice across the states can decrease by implementing a hospice policy on practices and regulations that would allow hospice access to all eligible individuals. This would decrease the disparity among non-African American and African American populations' hospice use. The more that hospice is accepted, the lower the racial disparity in the use of hospice. This study could increase awareness of factors on cancer and terminal illness in a unique age group and population.

Rich, Gruber-Baldini, Quinn, and Zimmerman (2009) analyzed data of 2,171 newly admitted African American and European American residents to 59 nursing homes and their significant others in structured interviews and chart reviews. Rich et al. linked racial disparity and advance directives completion to nursing home residents. African American residents and their families were less likely than European American residents to discuss treatment restrictions with physicians and nursing home staff. This could be attributed to a history of limited access to care, spiritual beliefs, as well as the expectation of health care providers and the quality of the facility. As a result of racial disparity in treatment restrictions, physicians and nursing home staff should establish a rapport with the residents and their families during the admission process in order to facilitate a discussion about advance directives completion using the proper choice of words (Rich et al.). By introducing treatment decisions early in the process, the residents and families will have the knowledge and guidance to make an informed decision for EOL and hospice care. Although, I did not explore nursing homes residents, I did explore the completion of advance directives among the African American military beneficiaries. In previous studies, completion of advance directives was mostly studied in the age group 65 and older (Bullock, 2011).

African American cancer patients are also less like to use hospice care. Ramsey and Chin (2012) examined the disparity existing in the African American patients with cancer and found that African American patients with cancer are more likely to disenroll from the services and not return to seek aggressive treatment, which yields a low usage rate. There was also an increased concern about hospice care from family members of the African American patients compared to European American family members. The study was limited to older African Americans patients aged 65 and over with cancer. This research topic included the African American military beneficiaries ages 18-64 who have a diagnosis of cancer and or terminal illnesses.

It has been noted the individual with noncancer diagnosis were more willing to use hospice more readily than individual with a diagnosis of cancer. Johnson et al. (2007) that indicated there is a correlation between disease and pattern of hospice use. Johnson et al, found that African American populations with noncancer diagnoses were more likely to use a hospice than the individuals with cancer diagnosis. Johnson et al. study was a quantitative design using secondary data from the VITAS Healthcare Corporation including African American and European American hospice enrollees who were discharged from hospice between January 1, 1999 and December 31, 2003. Johnson et al. suggested that increasing hospice use in the African American patients with noncancerous diagnoses would diminish racial disparity in the overall hospice use and improve the quality of care in the dying among this population.

Johnson, Kuchibhatla, and Tulsky (2011) examined racial differences in African Americans and European Americans patients who enrolled into home hospice care one to two days prior to transitioning to final stage of life. Johnson et al. also explored hospice preadmission location and hospice length of stay (LOS). The study was based on a three-year quantitative design obtaining data from VITAS Healthcare hospice provider program. Johnson et al. concluded that African-Americans are more likely to want aggressive therapies than European Americans and have higher rates of hospitalization, cardiopulmonary resuscitation, and in-hospital deaths. Johnson et al. further noted that African Americans as compared to European Americans had less knowledge about hospice care. This study explored the knowledge of hospice care among the African American military beneficiaries population in the age group of 18-64.

Fishman et al. (2009) examined 283 patients that were receiving treatment for cancer at six oncology clinics. Fishman et al. found that African American patients preferred aggressive cancer treatment and fifty percent of the patients in the study had an admitting diagnosis of cancer and a life expectancy of $\leq$ 6 months. It was recommended by Fishman et al. to redesign the hospice eligibility criteria to overcome health disparity between African Americans and European Americans.

Casarett et al. (2008) conducted a study on re-evaluating hospice eligibility criteria utilizing Medicare hospice benefit for those that are diagnosed with cancer. Patients who are eligible for Medicare hospice benefit have to be diagnosed with cancer and have a life expectancy of six months or less. The patients have to be willing to give up curative care, which leaves them with making a choice between hospice or aggressive care. Casarett et al. noted veterans who enroll in the Veterans Health Administration system are not under the same guidelines as the non veterans in the Hospice Medicare Benefit program.

Hospice and End-of-Life Decision-Making

EOL decisions are challenging for patients, family members, and health care providers. Radwany et al. (2009) suggested that during these difficult times, families should utilized palliative care consult services (PCCS) to provide support that are needed to make an informative decision that would be beneficial for everyone. The goal of this service is to make EOL decision making more understandable and acceptable. Radwany et al. conducted qualitative design grounded theory study interviewing 23 family members after the death of a loved one in an intensive care unit (ICU) to ascertain emotional burden and experiences that surrounded EOL decision making. Radwany et al. found three emerging themes that centered on emotional burden: the illness experience, decision making in the family meeting, and the dying process (p. 378). The final conclusion was more time should be spent with patient/family meetings regardless of the decision to continue aggressive treatment, hospice care, or do not resuscitate (DNR)/ do not intubate (DNI) status. It is important for health care team members to listen attentively, answer questions appropriately, and offer emotional support frequently.

Johnson et al. (2010) conducted an exploratory, retrospective review of 1072 deaths that occurred between January 1998 and June 2006 at Duke University cardiac care unit (CCU). Johnson et al. examined factors such as full code, DNR, and withdrawal of life support that would have some type of influence on the patients' choices when it comes to EOL care. In their final analysis, African Americans were 41.8% more likely than European Americans 26.7% to choose full code status, 37.3% of African Americans versus 43.9% European Americans were more than likely to choose DNR, and 20.9% African Americans versus European Americans were more than likely to choose full code status. The importance of this study contributed to identifying advance care planning as a significant factor associated with EOL care and underuse of hospice care in the African American population.

Tang, French, Cipher, and Rastogi (2012) conducted a retrospective study of patients in the Veteran's Affairs North Texas healthcare System (VA) that were referred to hospice. Hospice referrals are encouraged early in the EOL care in order for an individual to get the maximum benefits. Hospice is an avenue that can reduce the fear of dying alone while maintaining dignity during the final stage of life. Tang et al. explored veteran's length of stay and hospice referral from 2001 and 2010. Their primary participants were European American males over the age of 65. Tang et al. concluded hospice care was used more in 2010 than 2001 and there were no differences between the years in the length of stay, but little progress made with referring patients earlier. Hospice knowledge, referral, and advanced care planning in the terminally ill and cancer patients have not been studied in the younger military beneficiaries aged 18-64.

Bullock (2011) posited that there are some racial and ethnic differences when it comes to EOL preferences. These differences have caused some cultural barriers such as attitude and knowledge about hospice when it comes to making a decision about EOL preferences. Although there has been a steady rise in the enrollment of patients in hospice care, the underutilization rate among African American patients remains disproportionate to the European American patients. Bullock's findings were consistent with Yancu, Farmer, and Leahman (2010) that African Americans were less likely than European Americans to complete an advance care directive. It is important for providers to understand patient's cultural values, beliefs, and views when it comes to EOL decisions, as well as aggressive treatment.

Webb and Tucker (2009) explored factors that affected young adult opinion as it related to hospice as an EOL option and home death. Webb and Tucker examined the knowledge about hospice and the amount of exposure an individual had with the death of a loved one that had terminal illness. Webb and Tucker identified factors such as race/ethnicity, aggressive treatment, and advanced directives as contributing factors that influences choices about EOL care, hospice care and home death. African Americans were less likely than European Americans to have an advanced directives and select home death as an option, but likely to choose aggressive treatment.

Melhado and Byers (2011) conducted a systematic review of the literature from 1995 to 2010 to examine patterns or trends with patients and or their surrogates when making decisions about EOL care. They concluded there was a culmination of six patterns in the 19 qualitative studies that were associated with patients and or surrogate making the decision to withdraw, withhold, or continue life sustaining treatments. These patterns were communication, age, race, spiritual, psychosocial, and shared decision making (Melhado & Byers, 2011). As a result, African Americans were less likely than European Americans to withdraw or withhold life-sustaining treatments. Moreover, a lack of communication among patients and providers continues heighten the barrier with EOL decision making. I examined a different age group and factors that contribute to the underused rate of hospice care among the African American military beneficiaries population.

Hazin and Giles (2011) examined EOL care and theorized hospice care goals were to improve QOL and minimizing pain and suffering in patients with terminally illnesses; but these services continue to remain underused by the African American populations. Hazin and Giles suggested when it comes to terminally ill patients making provisions for EOL care; there is a color line. Despite all efforts, there continues to be barriers such as, spirituality, lack of public awareness, cultural perceptions, communication, and pain management that contributes to African Americans from utilizing palliative care and hospice services. African Americans associated EOL care with “giving up,” thereby demonstrating stronger preferences for aggressive care than their European American counterparts.

Mack, Paulk, Viswanath, and Prigerson (2010) studied the association of EOL communication disparity between African American and European American patients. A multi-institutional prospective longitudinal cohort study was conducted using 71 African American patients and 261 patients with advanced cancer. Mack et al. examined EOL discussions and communication goals that occurred between African American and European American patients with their physicians. Mack et al. revealed African American patients as a whole received more life-prolonging measures and less comfort care than their European American patients at the EOL. In their sample, it was noted that African American patients received inferior EOL care as it related to communication goals and the use of hospice care.

Mazanec, Daly, and Townsend (2010) examined multiple complex factors that influenced EOL decisions that affect all patients. These factors included “history of disparities and discrimination in health care, which had an influence on the family, family system beliefs, values, and practices, and health care system issues” (p. 560). Mazanec et al. used The Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatment (SUPPORT) to identify individuals would rather die at home as long as they have good pain control and less suffering. This is the ultimate goal of hospice philosophy that is consistently underused by the African American populations. Instead, the African

American populations preferred aggressive treatment as a form of EOL care even at the expense of suffering. Mack et al., 2010; Hazin and Giles, 2011; and Melhado and Byers, 2011 addressed racial and ethnic disparities among the African American population as it relates to the underused of hospice care toward the EOL decision.

Despite efforts for patients to make a decision about EOL care, advanced care directives still presents a challenge to the African American population. Yancu, Farmer, and Leahman (2010) used a cross-sectional sample of 314 adults aged 18 years and older in the North Carolina area to explore why African Americans utilized hospice care at a low rate. Yancu et al. used the univariate technique to examine the means, ranges, numbers, and percentages of the variables. The bivariate was used to explore the association between strength of the relationship and the resistance for not wanting to use hospice care. Yancu et al. found there was a lack of knowledge about hospice care among the African American population. It was also noted in the African American population that attitude played a major role as a cultural difference in death and dying. The preferred attitude of the African American population is to take care of their loved one at home. Yancu et al. also found that approximately 72% of African Americans were unlikely to complete an advanced care directive.

Hospice and Advanced Stage Diagnosis

Recognizing cancer as a major contributor to death and an increase need for improved EOL care and hospice in the advanced stages, Ford, Nietert, Zapka, Zoller, and Silvestri (2008) conducted a comparison study with caregivers and physicians of lung cancer patients using perceived barriers to hospice enrollments. The participants were from

South Carolina and recruited through a partnership with a local hospice organization between 2000 and 2004. Ford et al. found that from the caregiver's perspectives, the leading reasons patients were hesitant about enrolling in hospice is that the unanticipated transition from well to sick and hospice had the same connotation as giving up. On the other hand, from the physician's perspectives, earlier enrollment to hospice programs means patients will survived from lung cancer and the assumption of a DNR and DNI status were required prior to enrollment. The conclusion was that lung cancer patients would benefit from knowledge about hospice services in the early stages and more education about the disease process with a care plan.

Keyser et al. (2010) studied the impact of survival and intervention for noncurative gynecologic malignancies patients who relied on supportive care from 2002 to 2008. Keyser et al. found that the majority of their patients were European Americans who had recurrent ovarian cancer. According to Keyser et al., "approximately a third of patients die awaiting initiation of hospice care either at home or in an inpatient hospice unit. Many patients prefer to use aggressive intervention right up to the time of death" (p.275). Keyser et al. noted terminally ill patients who enrolled in hospice actually lived longer than those who did not, regardless of race. There is a need for patients to enroll in hospice early in the process at the beginning of discussion about EOL interventions.

According to Hardy et al. (2011), lung cancer is considered one the most common causes of death in the U.S., and is responsible for approximately 34% of hospice cancer deaths. Hardy et al. used the Surveillance Epidemiology, and End Results (SEER)-Medicare linked database to access information for lung cancer cases, hospice services, and vital status from 1991 to 1999. The focus was to explore whether there are any racial disparities for length of stay in hospice for patients with lung diseases. Hardy et al. found Blacks that were diagnosed with nonsmall cell lung cancer (NSCLC) in the advanced stages experienced a shorter length of stay in hospice. Hardy et al. noted several factors such as cultural beliefs, philosophy of hospice, ideas about hospice, distrust in the healthcare system, acceptance at the EOL, and cultural competence by heath care professionals that may preclude minorities in general from utilizing hospice services.

Huskamp et al. (2009) conducted a study utilizing metastatic lung cancer patients in the advanced stages. Huskamp et al. study was based on exploring factors such as lack of awareness of hospice, inaccurate understanding of one's prognosis, and preference for aggressive treatment to identify if physicians have discussed the possibility of hospice service with patients within the last seven months of diagnosis. As a result, Huskamp et al. found those patients who discussed hospice with their providers were more than likely to enroll in hospice program or services. African Americans and other minorities were less likely than European Americans to have had a discussion of hospice program or services. This was associated with physician lack of communication with their patients about the awareness of hospice and misunderstandings about their prognosis.

Givens, Tjia, Zhou, Emanuel, and Ash (2010) explored Medicare beneficiaries patients diagnosed with end-stage heart failure (HF) who can benefit from utilizing hospice care. Hospice care sole purpose is to provide comfort and emotional support to patients. Although, hospice programs and services can offered valuable benefits to those that are diagnosed with end-stage HF and other terminal illnesses, these services continues to be underused by patients of noncancer conditions. Givens et al. found Medicare beneficiaries with HF who are minorities were less likely than European Americans to use hospice care for HF. According to White (2013), African Americans with HF would rather rely on God to take control of their health and are empowered by their religious instead of utilizing hospice service.

Summary

Increasing the knowledge and philosophy of hospice care in the community, as well as educating the health care team on cultural values, attitudes, and beliefs, will be a step toward social change. The literature review supports the current research about factors that contributes to the underuse of hospice care in the African American population. African Americans are still presented with a challenge when it comes to putting their desires, needs, and wishes in an advanced care directives. African Americans rather seek aggressive care than to enroll in a hospice program, even if it means suffering. Hospice care is often viewed as a “taboo” in the African American population that has been associated with death. A stigma that will be overcome by educating patients, family members, and health care personnel about the philosophy and benefit of hospice care. The implication for social change in this study was to focus on the military beneficiaries to have the knowledge about hospice care that would be useful when making an EOL decision. It is important for the health care providers, social workers, discharge planners, and nurse to understand the patient’s cultural values, beliefs, and views when making EOL decisions.

An individual attitude plays a major role in cultural difference when it comes to death and dying. The main goal of hospice philosophy is to meet the comfort needs of the patient while providing them with an environment for a peaceful death. The theory that is utilized in health care arena is the CT. The CT focuses on three types of comfort, relief, ease, and renewal. Many medical institutions have adopted this theory as the framework for nurses who work with patients and families that are experiencing death and dying. This is not an easy task to face knowing you only have less than six month to be on this earth before transitioning over from labor to reward. Chapter 3 presented the methodology for this study, including population, sample, instrumentation, data collection and analysis, procedures, and safeguards for the ethical protection of participants.

Chapter 3: Research Method

Introduction

The purpose of this study was to explore the low use of hospice care in the African American military beneficiaries' population that could be attributed to a lack of knowledge, attitudes and beliefs, mistrust of the health care personnel, and advanced care plans. The research design, setting and sample, instrumentation and materials, data collection and analysis, and the ethical treatment of participants are discussed in this chapter.

Research Design and Rationale

The study was a quantitative, cross-sectional, correlational, descriptive, nonexperimental research design that was used to evaluate relationships among knowledge about hospice care, attitudes and beliefs regarding hospice, mistrust in the hospice health care system, advanced care planning, and participation in hospice care for terminally ill African Americans, ages 18-64. The purpose of this study was to evaluate the factors associated with the underuse of hospice care in a terminally diagnosed, African American military beneficiary population.

Quantitative research uses numbers and closed-ended questions. Creswell (2009) noted that quantitative research is "a means for testing objectives theories by examining the relationship among variables" (p. 233). Quantitative research designs are used to explore objectives that use a systematic strategy for generating and refining knowledge. The primary focus of a quantitative study is based on deductive reasoning and generalization (Sousa, Driessnack, & Mendes, 2007). Hopkins (2000) posited that quantitative research is descriptive or experimental, and it is used to determine the relationship between an independent variable and dependent variable in a population. In this study, the independent variable was race, which was used to predict a lack of knowledge, attitudes and beliefs, mistrust of the health care personnel, and advanced care plans, which were the dependent variables.

Nonexperimental research is used in a quantitative design to influence the independent variable and participants are selected randomly. Price (2012) stated that scholars use nonexperimental research when they lack the ability to manipulate the independent variable and the assignment of random participants to conditions or orders of conditions or both. The questions or hypothesis can be a single variable instead of having a statistical or noncausal relationship between two variables. According to Sousa et al. (2007), nonexperimental designs do not have random assignment, manipulated variables, or multiple groups that are observed in what is occurring in a nature way. Marczyk, DeMatteo, and Festinger (2005) argued that nonexperimental researchers could not rule out extraneous variables as the cause what is being studied and or observed because there is no control over the variables or environments. The most predominant design that is used in social sciences is a cross-sectional design.

Conducting a quantitative, cross-sectional, nonexperimental design has a couple of advantages. The first advantage of a cross-sectional design is it allows a researcher an opportunity to perform his/her study in natural, real life settings. The second advantage of a cross-sectional design is that it does not require a researcher to randomly assign individuals when comparing groups (Frankfort-Nachmias & Nachmias, 2008). By using this nonexperimental, cross-sectional design, the independent variable (hospice care) cannot be manipulated (Frankfort-Nachmias & Nachmias, 2008).

Other methodologies were taken into consideration, such as qualitative research design. Maxwell (2005) posited that a qualitative study is a process rather than an outcome. There are several strategies of inquiry within qualitative research and the one strategy of qualitative research that was taken into consideration for this study was the phenomenology. Patton (2002) noted that "a phenomenology asks for the very nature of a phenomenon, for that which makes as some-'thing' what it is-and without which it could not be what it is" (p. 104). Phenomenology is typically focused on past knowledge experiences in order to understand a phenomenon at a deeper height (Creswell, 2007). In this study, I explored factors in the African American beneficiary population who have accepted the diagnosis of a terminal illness that would prevent them from using hospice service. I selected not to use a phenomenological design because of the sensitivity of subject and looking through the lens of African Americans culture. Phenomenology strategy can be anxiety provoking for individuals who are faced with the inevitable of death and dying, which makes it difficult to talk about past experiences of their disease process. By using a survey design, it provided minimal risk without causing any type of harm or mental injury to the participants.

Setting and Sample

Participants were military patients who had accepted their diagnosis of a terminal illness from ambulatory care oncology, neurology, dialysis, and/or medical clinics located in the Northeastern portion of the United States. The population was a simple random sampling, and Health Insurance Portability and Accountability Act (HIPAA) and patient confidentiality was adhered to (Appendix E). The minimum size for this study was 29 participants with 18 African Americans and 11 European Americans surveyed. According to Frankfort-Nachmias and Nachmias (2008), a simple random sampling is a basic probability sampling and is denoted by the letter *N* assigned to a population group. This type of sampling was used for this study because it provided all units of the population to be included and had less of a probability of an error occurring with the sampling frame. The following inclusion criteria were as follows: African Americans and European Americans, non-Hispanic, male or female beneficiaries ages 18 to 64 who were willing to complete the survey, were able to read and comprehend English, and were diagnosed with a terminal illness. Exclusion criteria were as follows: ages 65 and older, inability to speak English and understand the consent form, and any condition that was deemed unsafe or unwanted, such as anything in this study which makes the individual uncomfortable or upset. The individual may choose to stop taking part at any time without any loss of medical care or benefits.

The SurveyMonkey questionnaire was posted on the facility's intranet under the research department icon for the participants to select and complete. As noted by Frankfort-Nachmias and Nachmias (2008), web surveys are faster than conducting telephone surveys and are less expensive for a researcher to administer than paper-and-pencil. It is a convenient tool for the participants to complete at their leisure and can yield a lot of information (Vogt, 2007). Because this study was conducted at a specialized location and population, the PI received approval from Institutional Review Boards (IRB) from Walden University and an outside agency. The first IRB approval was received through the Office of Human Research Protection from Walden University Number 12-01-14-0190136. The final IRB approval was received through the Office of Human Research Protection from Walter Reed National Medical Center Bethesda Number 409107. Prior to the commencement of the survey, I met with nurse manager and medical officer of the units who supported the study and it was determined that a computerized web-based survey using SurveyMonkey would not be feasible to administer due to the facility's intranet firewalls; therefore, I administered a paper and pencil survey to the participants. Participants were recruited from the clinics based on their diagnosis of a terminal illness. I took steps to protect the privacy of the participants, and the survey records were locked in a file. The survey administration time was approximately 15-20 minutes for each participant for period of 30 days.

A researcher can determined the probability that a null hypothesis will be rejected if it is false by conducting a statistical power analysis test. According to Cohen (1992), the statistical power analysis is a test used to determine the probability that the null hypothesis will be rejected when it is false. There are three indicators used to determine the statistical power: the significance criterion (α), the sample size (N), and the population effect size (ES). Frankfort-Nachmias and Nachmias (2008) explained that the standard level of significance (α) is normally represented at .05 or.01, which means that the null hypothesis will be rejected if the outcome of the results occurred by chance 5% or 1% of the time. Although there is a small chance that a researcher can get the outcome of the results wrong, which will result into two mistakes: Type I and Type II error. According to Field (2009),

> A Type I occurs when we believe that there is a genuine effect in our population, when in fact there isn't and Type II occurs when we believe that there is no effect in the population when, in reality, there is. (p. 56).

An acceptable level of power is .80, making Type II error 4 times more likely to occur than a Type I error (Cohen, 1992). For this research, the α level was set at .05 and level of power .80, which is the standard acceptable level unless otherwise stated(Cohen,1992).

In quantitative research, an effect size is small, medium, or large and can be determined by performing different analyses. Field (2009) explained that an effect size is an objective that is usually measured by a standardized scale of observed effect. Effect sizes are usually defined as small, medium, and large. There were several different analyses used in this study to include *t* tests and multivariate analyses. Cohen (1992) indicated that when a *t* test is used, the effect size for small is .20, medium is .50, and large is .80. Field suggested the test when *r* is equal to 0, the effect size for small is .10, medium is .30, and large is .50. For this study, a medium effect size of .50, an acceptable power of .80, and level of significance .05, using G* power 3.1.9.2 software, was used, which is most commonly used in social science research. The sample size for this study was 29 participants, which yielded 26 participants to achieve validity.

Instrumentation

The questionnaire was based on a modified Hospice Barriers and Values Scales, Healthcare System Distrust Scale, and End-of-Life Care Survey developed by Johnson et al. (2008), and it was reviewed for face validity, and each scale tested for reliability using the Cronbach's alpha (Appendix C). The questionnaire was used in the past in populations aged 65 and older (Johnson et al., 2008). The questionnaire for this study was used to predict the factors that would have a significant impact on the use of hospice care in the African American military beneficiary population. This questionnaire, to my knowledge, had not been used in this age group or population, which made it unique and applicable for this study. The EOL survey (Johnson et al., 2008) is in the public domain, and permission was granted from the lead contributing author for its use in this study (Appendix B). The Hospice Barriers and Values Scales and Healthcare System Distrust Scale were published materials in the PubMed Central public domain and maybe used without permission as long as the source is properly cited and acknowledged in the paper. The EOL survey consists of four scales: hospice attitudes and beliefs, beliefs about dying and advance care planning, preferences for EOL care, and trust in the health care system. Demographic information such as age, ethnicity, education, gender, and marital status were assessed (Appendix D).

Reliability

The participants used a 5-point Likert scale that ranged from *strongly agree* to *strongly disagree*. Vogt (2007) indicated that "the Likert scale was named the researcher who pioneered it with choices ranging from strongly agree through neutral to strongly disagree" (p. 88). The Likert scale is the most common format for survey questions in social science research. The Cronbach's alpha test is used to correlate how closely related a set of items are as a group, which is a correlational measure of reliability, or it can measure the consistency of the items in a scale. Cronbach's alpha usually ranges are from 0 to 1.0, and the cutoff point for a reliable scale is 0.70 or higher (Vogt, 2007). The average Cronbach's alpha for the scales used in this study was 0.74.

Face Validity

A panel of EOL care researchers and clinicians assessed the questionnaire face validity. According to Frankfort-Nachmias and Nachmias (2008), "face validity is the investigators' subjective evaluation of the validity (appropriateness) of a measuring instrument" (p. 519). The preferences for the EOL care scale consisted of eight statements on the beliefs about an individual who is diagnosed with a terminal illness who has a desire or wish to live as long as possible even if it means to make the choice of being on life support, being brain dead, always receiving nutrition through a tube, or continuing to be in severe pain (Johnson et al., 2008). The scores for this scale ranged from 8 to 40, and the Cronbach's alpha was 0.71. The Advanced Care Planning scale included seven statements about the individual inevitability of death and the ease of discussing death. The scores for this scale ranged from 7 to 35, and the Cronbach's alpha was 0.75 (Johnson et al., 2008). The Health Care System Distrust Scale consisted of 10 items on the perception of health care system honesty, competence, and fidelity. The scores this scale ranged from 10 to 50, and the Cronbach's alpha was 0.75 (Johnson et al., 2008). The Hospice Attitudes and Beliefs Scale consisted of eight statements on an individual's attitude towards hospice care. The scores for this scale ranged from 8 to 40, and the Cronbach's alpha was 0.74 (Johnson et al., 2008). For this study, the questionnaire was modified to accommodate variables associated with the awareness and underuse of hospice services in a certain age group and population.

Data Collection

The modified Hospice Barriers and Values Scales, Healthcare System Distrust Scale, and End-of-Life Care Survey were distributed to participants who were military beneficiary patients who were diagnosed and had accepted a terminal illness. The participants were between the ages of 18-64 and were enrolled in designated ambulatory care oncology clinics. I informed the staff of the clinics at their morning report about the research protocol and the intent of the study. The participants were recruited from the clinics based on the diagnosis of a terminal illness and ages 18-64. Those who were eligible based on the inclusion criteria read the facility's research information sheet where they indicated their willingness to participate in the study (Appendix E). The participants understood that their care would remain the same if they chose to participate or not to participate.

Patients' demographics, knowledge of hospice care, preferences for care, and trust in the health care system were collected in this study. I administered the survey to each participant and was available to assist with any questions. Steps were taken to protect patient privacy, and only approved study personnel were allowed to access the survey. I kept the surveys in a locked file while maintaining the confidentiality of the information collected during the study under existing security, regulations, and laws.

Data Analysis

Data were entered into the Statistical Package for the Social Sciences (SPSS) version 21.0 for Windows (2010). Demographic data were analyzed using descriptive statistics to include the frequencies and percentages for nominal data and means and standard deviations for continuous data. Kaufman and Kaufman (2005) posited that descriptive statistics is a method used to describe the data collected from research studies in order to characterize the variables, which are under observation in a specific sample. For this study, a MANOVA was used to test the difference between dependent variables. Field (2009) noted that a MANOVA is used when there are several dependent variables to be measured. Each research question and data analysis procedures were described. The hypotheses were stated in the null and alternative form.

Research Question 1: Is there a statistically significant difference among African American military beneficiary population ages 18-64 as compared to other groups related to their knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans?

$H_0$1a: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to the lack of knowledge about hospice care.

H_a1a: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to the lack of knowledge about hospice care.

H$_0$1b: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to attitudes and beliefs about hospice.

H$_a$1b: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to attitudes and beliefs about hospice.

H$_0$1c: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to distrust in the health care system.

H$_a$1c: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to distrust in the health care system.

H$_0$1d: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to advanced care plans.

H$_a$1d: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to advanced care plans.

The research question was examined using the MANOVA. As stated by Field (2009), a MANOVA test is designed to explore several dependent variables (outcomes) simultaneously instead of using several analyses of variance (ANOVA), which will lend to a greater chance of making a Type I error. There are four different multivariate tests that can be conducted in SPSS comparing the ratio of effects of systematic to unsystematic variance for dependent variables (Field, 2009). The assumptions of multivariate normality and homogeneity of covariance matrices was assessed. The multivariate normality can be tested using the Kolmogorov-Smirnov (KS) test. Homogeneity of covariance matrices assumed the population of variance covariance matrixes; the analysis was equal in the different groups. The Levene's test can assess for the equality of covariance.

Ethical Procedures

Typically, all studies that involve any human participants pose some degree of risk. Some of these risks can be caused by form of discomfort or embarrassment when presenting the participants with a questionnaire that is considered a little intrusive or provocative (Kaufman & Kaufman, 2005). On a societal level, this could present an ethical dilemma; but there is guidance and principles to prevent such dilemmas. The survey participants were respected as a person. They had the right to make their own decision about whether or not they want to participate in the study. The facility information sheet was given to each participant who met the eligibility criteria for the study. The participants were given as much time as necessary to read through the facility's information sheet and was allowed time to ask any questions they had prior to completing the survey. By completing the survey implied consent to the study. The participants were free from any type of coercion and it was made clear that no treatments will be withheld or influenced by participating in the study.

The participants were informed there will be no risk or harm by participating in the study. The purpose of the study was explained as well as the benefits for their participation and maybe some sensitive information with questions as they relate to death and dying. Participants were informed if something in this study made them feels uncomfortable or upset; they may choose to stop taking part at any time without loss of medical care or benefits. Permission to collect data was obtained through the Walter Reed National Military Medical Center Bethesda IRB Approval Number 409107 and Walden University IRB Approval Number 12-01-14-0190136. The participants were informed there would be no bias or discrimination with the recruiting process. Participants were randomly selected. Their rights and confidentiality was protected. I maintained the questionnaire information collected during the study in a locked file. All necessary steps were taken to avoid any possible discomfort, embarrassment, or harm to any of the participants. Participants had the right to withdraw from the study at any time. They were informed that all information would be deleted upon withdrawal.

Summary

This chapter was a presentation of the research plan. The plan incorporated a quantitative, cross-sectional correlational, descriptive, nonexperimental research design. It involved two unique groups of individuals: African American and European American, non-Hispanic military beneficiaries in the aged group of 18-64. The modified Hospice Barriers and Values Scales, Healthcare System Distrust Scale, and End-of-Life Care Survey instrument supported the study variables. The SPSS 21.0 version for Windows (2010) was used for statistical analysis for the contributing factors such as the lack of knowledge about hospice care, attitudes and beliefs about hospice, preference for care and advance care planning, and mistrust in the healthcare system in the underutilization rate of hospice care among the African American beneficiary population ages 18-64. Descriptive statistics, MANOVA, and results will be presented in Chapter 4.

Chapter 4: Results

Introduction

This chapter includes the results of the study. The purpose of this study was to determine the reason or reasons for the low use of hospice care in the African American military beneficiaries' population aged 18-64 and to promote more effective educational and informational programs about hospice. Using the EOL survey, the objectives of the study were to determine factors that contribute to the underuse of hospice service in African American military beneficiaries who have a terminal diagnosis. Specifically, I addressed the following research question and hypotheses:

Research Question 1: Is there a statistically significant difference among African American military beneficiary population ages 18-64 as compared to other groups related to their knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans?

$H_0$1a: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to the lack of knowledge about hospice care.

H_a1a: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to the lack of knowledge about hospice care.

$H_0$1b: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to attitudes and beliefs about hospice.

H_a1b: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to attitudes and beliefs about hospice.

$H_0$1c: There is no significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to distrust in the health care system.

H_a1c: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to distrust in the health care system.

$H_0$1d: There is no significant difference in the low use rate of hospice Care among the African Americans military beneficiary population in the age group of 18-64 in relation to advanced care plans.

H_a1d: There is a significant difference in the low use rate of hospice care among the African Americans military beneficiary population in the age group of 18-64 in relation to advanced care plans.

In this chapter, I describe the data collection and characteristics of the sample, including race, gender, marital status, living children, education, and health. The chapter includes a description of data cleaning procedures, which included checking for missing cases and the presence of outliers. Next, a Cronbach's alpha reliability analysis of the study subscales is reported. This is followed by the analyses of the research question. A MANOVA was conducted in order to determine if knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care significantly differed based on race. Finally, the information on data collection procedures, analysis of the data used to address the research question, and a summary are presented.

Data Collection

The study was a quantitative, cross-sectional, correlational, descriptive, nonexperimental research design. The only discrepancy in data collection from the plan in Chapter 3 was it had been anticipated that the questionnaire would be posted on the facility's intranet using SurveyMonkey under the research department icon for the participants to select and complete. Instead, a paper and pencil survey was administered approximately 15-20 minutes to each participant for a period 30 days. A total of 32 African American and non-African American military beneficiaries in the age category of 18-64 completed the study survey (Appendix C). Three participants were excluded from the analysis for not completing all of survey measures, leaving a final total of 29 participants. A posthoc power analysis was conducted using G*Power 3.1.9.2 in order to determine the statistical power achieved for the final sample of participants. The power analysis was based on a MANOVA with two comparison groups, four dependent variables, and a final sample size of 29. In the power analysis, I assumed a medium effect size and a significance level of .05. Given these parameters, the power level achieved in this study was .29.

Table 2 displays the frequencies and percentages for the sample characteristics. A majority of participants (62.1%, *n* = 18) were African American. Among the participants in the study, 51.7% were men (*n* = 15), and 48.3% were women (*n* = 14). Twelve participants were married (41.4%), and seven were divorced (24.1%). Nineteen participants (65.5%) had living children, and 10 participants (34.5%) did not have living children. The participant's highest percentage was college graduates (34.5%, *n* = 10), and 31.0% of participants had completed some college or technical training beyond high school (*n* = 9). The health of most participants was either good (34.5%, *n* = 10) or fair (31.0%, *n* = 9).

Table 2

Frequencies and Percentages for Sample Characteristics (N=29)

Variable	*N*	%
Race		
African American	18	62.1
White American, Non Hispanic	11	37.9
Gender		
Male	15	51.7
Female	14	48.3
Marital Status		
Single, never married	4	13.8
Married	12	41.4
Separated	3	10.3
Divorced	7	24.1
Widowed	3	10.3
Have living children?		
Yes	10	34.5
No	19	65.5
Education		
High school graduate or GED	4	13.8
Some college or technical training beyond high school	9	31.0
College graduate	10	34.5
Post-graduate or professional degree	6	20.7
Health		
Very good health	6	20.7
Good health	10	34.5
Fair health	9	31.0
Poor health	4	13.8

***Note.* Not all percentages may add to 100.0% due to rounding error.**

Results

Preanalysis Data Cleaning

Prior to the main analysis, the data were examined for missing cases and outliers. The initial number of participants was 32. However, three participants were excluded from the analysis for not completing all of the survey measures. The presence of outliers was checked using standardized values. Standardized values were calculated for each of the study subscales (i.e., age, knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans). Tabachnick and Fidell (2012) suggested that a score with standardized values greater than 3.29 or less than -3.29 should be considered outliers. There were no outliers found among the dependent variables. Analyses were conducted on a final sample of 29 participants.

Reliability Analysis

The interitem reliability of each of set of subscale items; that is, knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans was assessed using Cronbach's alpha. Cronbach's alpha provides the mean correlation (reliability coefficient) between each pair of items in a scale. Reliability coefficients of .7 or greater indicate acceptable interitem reliability (George & Mallery, 2010). Table 3 displays the number of items for each of the dependent variables, as well as the reliability coefficients. The reliability coefficients for two variables (i.e., distrust in health care system and attitudes and beliefs about hospice) were greater than .8, indicating good interitem reliability for these measures. Results for knowledge of hospice indicate acceptable reliability ($\alpha = .70$). Initially, reliability for advanced care plans was poor (α = .50). An examination of the interitem correlations revealed that the reliability could be improved by removing Q2 from the scale.

After removing this item, the reliability for advanced care plans was accepted (α = .72). Next, composite scores were created for knowledge of hospice care, attitudes and beliefs about hospice, and distrust in the healthcare system by summing the responses to each item in the scale and dividing by the number of responses. For advanced care plans, responses were coded as “yes” = 1 and “no” = 0. These responses were summed to create the composite score for advanced care plans. Table 4 displays maximums, minimums, means and standard deviations for each of the composite measures as well as age.

Table 3

Reliability Coefficients for Dependent Variables

Variable	Number of Items	Cronbach’s Alpha
Knowledge of hospice care	8	.70
Distrust in healthcare system	10	.88
Attitudes and beliefs about hospice	7	.80
Advanced care plans	5*	.72

Note. *Q2 was removed from the composite score due to poor initial reliability.

Table 4

Descriptive Statistics of Continuous Variables

Continuous Variables	*Min.*	*Max.*	*M*	*SD*
Age	47.00	76.00	58.62	6.92
Knowledge of hospice care	1.38	4.50	2.75	0.73
Distrust in healthcare system	1.00	5.00	3.20	1.06
Attitudes and beliefs about hospice	1.00	5.00	2.36	1.03
Advanced care plans	0.00	5.00	2.90	1.61

Face Validity

The questionnaire was assessed for face validity by a panel of end-of-life care researchers and clinicians. According to Frankfort-Nachmias and Nachmias (2008), "face validity is the investigators' subjective evaluation of the validity (appropriateness) of a measuring instrument" (p.519). The preferences for EOL care scale consisted of eight statements that explored beliefs about an individual that is diagnosed with a terminal illness and has the desire or wish to live as long as possible, even if it means to make the choice of being on life support, brain dead, always receiving nutrition through a tube, or continue to be in severe pain (Johnson et al., 2008). The scores for this scale ranged from 8 to 40 and the Cronbach alpha was 0.71. The Advanced Care Planning scale included seven statements examining belief about the individual inevitability of death and the ease of discussing death. The scores for this scale ranged from 7 to 35 and the Cronbach alpha was 0.75 (Johnson et al., 2008).

The Health Care System Distrust Scale consisted of 10 items that explored the perception of healthcare system honesty, competence, and fidelity. The scores this scale ranged from 10 to 50 and the Cronbach alpha was 0.75 (Johnson et al., 2008). The Hospice Attitudes and Beliefs Scale consisted of eight statements that addressed an individual attitude towards hospice care. The scores for this scale ranged from 8 to 40 and the Cronbach alpha was 0.74 (Johnson et al., 2008). For this study, the questionnaire was modified to accommodate variables associated with the awareness and underutilization of hospice services in a certain age group and population.

Research Question

To address the research question, a one-way MANOVA was conducted. The dependent variables in the analysis were knowledge of hospice care, attitudes and beliefs about hospice, distrust in the healthcare system, and advanced care. The independent variable in this analysis was race. Statistical significance was determined at $\alpha = .05$.

Prior to analysis, the assumptions of the MANOVA were assessed. Normality of the dependent variables was assessed with Kolmogorov Smirnov (KS) tests. The results of the KS tests indicated statistical significance for the knowledge of hospice care ($p = .007$) and advanced care plans ($p = .004$); thus, the assumption was not met for these variables, and I accepted the alternative hypothesis.

$H_0 1$a: There is no significant difference in the low utilization rate of Hospice Care among the African Americans military beneficiary population in the age group of 18-64 in relation to the lack of knowledge about hospice care.

$H_0$1d: There is no significant difference in the low utilization rate of Hospice Care among the African Americans military beneficiary population in the age group of 18-64 in relation to advanced care plans.

The KS test did not indicate significance for distrust in the healthcare system (p = .200) and attitudes and beliefs about hospice (p = .051); therefore, the assumption was met for these variables; therefore, I accepted the null hypothesis.

$H_0$1b: There is no significant difference in the low utilization rate of Hospice Care among the African Americans military beneficiary population in the age group of 18-64 in relation to attitudes and beliefs about hospice.

$H_0$1c: There is no significant difference in the low utilization rate of Hospice Care among the African Americans military beneficiary population in the age group of 18-64 in relation to distrust in the healthcare system.

Homogeneity of variance was assessed with Levene's tests. The results were statistically significant for distrust in the health care system (p = .002) and attitudes and beliefs about hospice (p = .019); thus the assumption was not met for these variables. The results of Levene's test were not statistically significant for knowledge of hospice care (p = .244*)* and advanced care plans (p = .496); thus, the assumption was met for these variables; therefore, I accepted the null hypothesis.

$H_0$1a: There is no significant difference in the low utilization rate of Hospice Care among the African Americans military beneficiary population in the age group of 18-64 in relation to the lack of knowledge about hospice care.

$H_0$1d: There is no significant difference in the low utilization rate of Hospice Care among the African Americans military beneficiary population in the age group of 18-64 in relation to advanced care plans.

Finally, homogeneity of covariance was assessed with Box's M test (Pallant, 2007). The results were statistically significant (p = .010); thus, the assumption was not met. Since the assumptions of MANOVA were violated, the most robust version of the *F*-test (Pillai's Trace) was used for the analysis.

The results of the MANOVA were not significant ($F(4, 24) = 1.04$, p = .406, partial η^2 = .148). This result indicates that participants did not differ in knowledge of hospice care, attitudes and beliefs about hospice, distrust in the healthcare system, and advanced care plans based on race. Therefore, I accepted the alternative hypotheses ($H_0$1a – $H_0$1d) of the study. Table 5 displays the means and standard deviations for each dependent variable by race.

Table 5

Means and Standard Deviations for Dependent Variables by Race

Dependent Variable	*Race*	*M*	*SE*
Knowledge of hospice care	African American	2.76	0.17
	White American, Non-Hispanic	2.74	0.22
Distrust in healthcare system	African American	2.93	0.24
	White American, Non-Hispanic	3.64	0.31
Attitudes and beliefs about hospice	African American	2.28	0.25
	White American, Non-Hispanic	2.48	0.32
Advanced care plans	African American	2.94	0.39

	White American, Non-Hispanic	2.82	0.49

Summary

This chapter was a presentation of the results of the analysis conducted to address the research question of this study. The results showed that there were no significant differences in knowledge of hospice care, attitudes and beliefs about hospice, distrust in the healthcare system, and advanced care plans based on race. Thus, I accepted the alternative hypotheses $H_0$1a, $H_0$1b, $H_0$1c, and $H_0$1d. Chapter 5 provides the interpretations of findings and the limitations of the study results that were discussed in Chapter 4. The implications for social change, recommendation for other populations, and future research are discussed in Chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this quantitative research study was to test which of the dependent variables was the possible reason for the low underuse of hospice service in African American military beneficiary population ages 18-64. In the research question, I assessed whether there was a relationship between the low use of hospice care among the African American military beneficiaries ages 18-64 and the lack of knowledge about hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans. A modified Hospice Values and Barriers Scales, Healthcare System Distrust Scale, and the End Of Life care survey developed by Johnson et al. (2008) was used to predict factors that may have contributed to the low use of hospice care among the African American military beneficiary population in this particular age group.

According to the findings of the study, there was no difference between African American and European American, non-Hispanics military beneficiaries who had accepted the diagnosis of a life limiting illness and making a decision about EOL care. The number of responses was limited due to the uniqueness of the military health care system population that different from the civilian population. Perhaps, repeating this study with a larger military population using more than one medical treatment facilities would yield better outcomes to institute an effective educational and informational program about hospice care in military medicine.

Scholars have suggested that the lack of trust in the conventional medical care, attitudes about hospice, and the lack of advanced directives may be factors that prevent

African Americans from using hospice to its fullest potential. According to the NHPCO (2015), approximately 1.6 to 1.7 million patients in the United States will received some type of services from hospice care. However, African American military beneficiaries in the age category of 18-64 who are terminally ill in medical treatment facilities are consistently not benefitting from the support that hospice provides (Connor et al., 2008; Dussen et al., 2011). However, the age group rarely included is the military beneficiary group ages 18-64 (Carrion et al., 2012; Frahm et al., 2011; Johnson et al., 2008; Manu et al., 2012). A gap remains in the research on identifying the lack of knowledge about hospice care, attitudes and beliefs about hospice care, and mistrust of the health care system as the factors for not using hospice care in a military setting. This chapter includes an interpretation of the research findings, limitations of the study, recommendations for further research, implications for social change, and conclusion.

Interpretation of the Findings

The current study was unique because of its targeted population of African American military participants and location. I attempted to address a gap in the literature by determining the contributory factors for the low use of hospice care in the African American military beneficiaries' population in aged 18-64. In order to understand the low use of hospice care among the African American military beneficiaries, it was imperative to identify the contributory factors. By identifying the contributory factors to the low use of hospice care this could promote an effective educational and informational programs.

I found no statistically significant differences in knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans based on race, $P>.05$. A majority of the participants had heard about hospice, would want to use hospice, and felt comfortable talking about dying; however, the service still remains underused by the African American population.

The dependent variables in this study were knowledge of hospice care, attitudes and beliefs about hospice care, distrust in the health care system, and advanced care plans, and the independent variable was race. A MANOVA was conducted using the statistical significance at $\alpha =. 05$. Overall, the participants did not differ in knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans based on race; therefore, I accepted the alternative hypothesis ($F(4,24) = 1.04$, $P = .406$, partial $\eta^2 = .148$).

The results of this study are consistent with the comfort theory, which is used in the health care arena. It provides an avenue for patients and families to make that link to the next phase of transitioning. Opportunities exist for further researchers to assess other minority groups to address factors that contribute to the low use of hospice services among minority groups.

Limitations of the Study

The first limitation of the study was the location. All of the participants were from one military treatment facility; no other military treatment facilities and or nursing homes were used in this study, and the results may not be generalizable to other populations of beneficiaries. The sample size consisted of 32 participants; three participants were excluded from the analysis for not completing all of the survey measures, leaving a final total of 29 (18 African American, 11 European American, non-Hispanic) who completed the survey. Expanding the survey to a wider population of beneficiaries at more than one military treatment facilities could result in better responses with reason why hospice care is not used among minorities.

The final limitation of the study was the computer-web access for the survey. I had anticipated that the questionnaire would be posted on the facility's intranet using Survey Monkey for the participants to select and complete. Prior to the commencement of the survey and approval of the IRB through the Office of Human Research Protection from Walden University and facility IRB, I met with the nurse manager and medical officer of the units who supported the study. It was determined at that time a computerized, web-based survey would not be feasible to administer due to the facility's intranet firewalls. For future study, an alternate plan such as pencil and paper surveys will need to be considered when utilizing a federal agency to minimize any steps or problems with the facility's intranet firewalls.

Recommendations

Further research is warranted to address the limitations of this study. The results of this study did not show any difference with age, military status, and or race as it relates to knowledge of hospice care, attitudes and beliefs about hospice, distrust in the health care system, and advanced care plans. Johnson et al. (2008) identified that cultural beliefs and values accounted for differences between African American and European American use of advance directives and attitudes and beliefs about hospice care. Dussen et al. (2011) indicated that the lack of knowledge and attitudes about hospice care and EOL issues are factors that contribute to the low use of hospice services among the African American population and other minority groups. Although I did not find a different in relationship between race and the variables, the recommendation is for a replication of this study using a larger sample and to include other minority groups at more than one military treatment facility and or medical centers. Capturing a larger sample of minorities to assess the lack of knowledge about hospice care and other contributory factors is also recommended. I recommend that the material be disseminated in the format of a DVD and CD in diverse languages to the staff and patients to assist with increasing the knowledge and awareness of hospice (Carrion et al., 2012).

Other factors that could have been included in the study are: lack of diversity in hospice team, religious beliefs, hospital admission criteria, and insurance (Tang et al., 2012). This study could also be replicated using a qualitative research approach. The researcher could use a phenomenological approach. Qualitative data could be gathered through interviews of African Americans military beneficiaries and other minorities who have accepted the diagnosis of a terminal illness. Creswell (2007) noted phenomenology typically focuses on past knowledge experiences in order to understand that phenomenon in a deeper level. Researchers interested in this topic could use this analysis to assist with their findings to strengthen the understanding of the low use rate of hospice care among the African American compared to other minorities in the same age group by exploring factors such as aggressive care, religious beliefs, and discrimination in the U.S.

Implications for Social Change

The research has shown that individuals with a level of understanding about hospice care can benefit from the different types of hospice services. According to the NHPCO (2015), it was estimated in 2014 that approximately 1.6 to 1.7 million patients will benefit from utilizing some type of services from hospice care. Only 7.6% African Americans benefited from using hospice services as compared to 76.0% of European Americans. Despite the low numbers in this population, it is imperative that information about the knowledge of hospice care, the attitudes and beliefs about hospice care, and preference for care information be disseminated among African Americans populations in a forum that everyone would be able to receive the same level of understanding. In this study, I examined key factors that were considered to be contributing factors to the low use rate of hospice care among the African American military beneficiary population. There were no statistically significant differences in the knowledge of hospice care, attitudes and beliefs about hospice, distrust in the healthcare system, and advanced care plans based on race.

This study does not offer direct benefit to participants. However, the findings can contribute to making an informed decision about the use of hospice for all military personnel who are engaged with terminally ill patients at the time of diagnosis. To increase the awareness about the benefits of hospice services, brochures and poster presentations can be distributed throughout the facility and institute a policy for annual hospice awareness in-service training for health care team members. These programs and the value of its benefits about hospice awareness can be generalized to other minority groups. The implications of this study would include making recommendations to the military policy makers and administrators in health services to focus on improving the quality of the EOL for terminally ill patients. This study would have an impact in the field of Public Health, Healthcare Administration, and Health Literacy by enhancing the current practices and protocols for the terminally ill patients across military medicines.

Conclusion

This study was conducted to determine the factors that contributed to the low use of hospice care in the African American military beneficiaries population ages 18-64. The evidence of this study did not support the researcher hypothesis. However, the results of Levene's tests were statistically significant for distrust in the health care system and attitudes and beliefs about hospice, thus the assumptions for these two variables were not met. In contrast to the other two variables; knowledge of hospice care and advanced care plans, which were not statistically significant and the assumption was met. There is a need for more research to be done in this area, as well as gaining a better understanding of the multiple factors that may impact the quality of EOL processes; and factors that may influence the use of hospice services in the African American population ages 18 to 64 years. It is importance to support an optimal QOL experience for the patient and families during the EOL process and understand that African American need to have social support from their family and friends. These are the individuals who can communicate their wishes to the providers. Hospice services are designed to provide a holistic approach to transitioning loved ones, while maintaining the dignity of the patient and the family across a diverse demographic. The African American population has not been adequately studied in its use, barriers, and outcomes with hospice services and understanding of their traditions, values, and preferences for care. This study has provided yet another gateway to further this endeavor.

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Appendix A: Partnership Letter

EDUCATION PARTNERSHIP AGREEMENT

BETWEEN

WALDEN UNIVERSITY

AND THE

WALTER REED NATIONAL MILITARY MEDICAL CENTER

Subject: Educational Partnership Agreement

1. This Education Partnership Agreement is entered into by and between Walden University, located at 100 Washington Avenue South, Suite 900, Minneapolis, MN 55401, and Walter Reed National Military Medical Center (hereinafter "WRNMMC"), located at 8901 Wisconsin Avenue, Bethesda, MD 20889. When referred to collectively, Walden University and WRNMMC are referred to as the "Parties".

2. <u>Background</u>:

a. Congress enacted Public Law 101-510 (5 November 1990) and Title 10 United States Code Section 2194, Education Partnerships, for the purpose of encouraging and enhancing study in scientific disciplines at all levels of education. Title 10 United States Code Section 2194, Education Partnerships, requires the Secretary of Defense to authorize each defense laboratory to enter into one or more Education Partnership Agreements with educational institutions in the United States, including local education agencies, colleges, universities and nonprofit institutions that are dedicated to improving science, mathematics and engineering education. Department of Defense (DOD) Directive 5535.3, DOD Domestic Technology Transfer (T2) Program, dated May 21, 1999, and DOD Instruction 5535.8, DOD Technology Transfer (T2) Program, dated May 14, 1999 implemented 10 USC 2194 to the DOD. Joint Task Force National Capital Region Medical Instruction 5535.01, Domestic Technology Transfer (T2), dated March 27, 2012, implements these provisions for WRNMMC.

b. WRNMMC, having a history of world-class research and development, possesses a broad spectrum of skills, facilities, personnel, special equipment, information, computer software and know-how pertaining to the care and rehabilitation of patients, in particular Service Members (active, reserve, retired) and their family members.

c. The Parties desire to cooperate in developing a Program under which Walden University students in various disciplines, including communication, science, technology, mathematics, engineering, and computer science may be given academic credit for work on defense laboratory research projects.

d. Walden University desires to involve its faculty and students in utilizing the outstanding scientific and technological resources of WRNMMC.

3. Purpose: The purpose of this Education Partnership Agreement is to aid in the education of Walden University students by providing a mechanism by which selected students can undertake research projects and by which Walden University students and faculty can benefit from WRNMMC's staff expertise, unique facilities and equipment at WRNMMC. Among other things, WRNMMC's contributions will help to encourage student interest in the treatment and rehabilitation of Service Members and their families and may benefit the laboratory in terms of advance training of future employees. This may benefit the country by exposing students to career opportunities in government research and development.

4. Requirements:

   a. Responsibilities of WRNMMC:

   (1) WRNMMC may loan defense laboratory equipment to Walden University for educational purposes.

   (2) WRNMMC may provide personnel, equipment, and facilities to establish a program to allow selected Walden University students the opportunity to work at WRNMMC on research projects.

   (3) WRNMMC may suggest projects suitable for student participation. It is understood that projects will normally be of an extent and sophistication commensurate with either senior level undergraduate or advanced degree work. WRNMMC will also be responsible for determining if any laboratory research and development project on which a Walden University student or faculty member works or is involved with contains information that is proprietary or restricted for export or military critical technologies, requiring Walden University students or faculty members to comply with paragraph 7b of this Agreement.

   (4) WRNMMC may require Walden University faculty and students to sign agreements restricting disclosure of certain information as a condition of Program participation.

   (5) WRNMMC will guide students to ensure that projects meet the standards of Walden University and WRNMMC. Student projects should be structured along the lines of typical laboratory work and therefore be representative of meaningful on-the-job experience.

   (6) In accordance with Federal policy, WRNMMC will place a priority on accepting students suggested by Walden University who are women, members of minority groups, or other groups of individuals who are traditionally involved in science and engineering professions in disproportionately low numbers.

   (7) The level of effort to be expended by WRNMMC on any activity under this Agreement shall be within the discretion of WRNMMC.

   b. Responsibilities of Walden University:

(1) Walden University will specifically designate a faculty member to serve as liaison with WRNMMC concerning the structure and conduct of this Program. Additionally, each student involved in work with WRNMMC will have a faculty advisor appointed by Walden University. The Walden University faculty advisor will work with the student and WRNMMC staff in a cooperative effort to guide and monitor the student's work at WRNMMC. The Walden University faculty advisor will have final responsibility for determining the student's course grade after consultation with WRNMMC staff.

(2) Walden University may grant academic credit in the appropriate degree program to students who satisfactorily complete participation in the Program in accordance with Walden University policies.

  a. Undergraduate students participating may obtain academic credit through an appropriate senior level project-oriented course of their degree program. The course requirements would include a formal written and/or oral report of project results.

  b. Graduate student involvement will usually be in the form of work that may serve as the basis for a thesis or a project. The student's advisor will serve as the faculty advisor described in paragraph 4(b)(1).

(3) Walden University will obtain prior written approval from WRNMMC before acknowledging WRNMMC participation in any report or thesis, or subsequent presentations or publications resulting from work performed under this Agreement. The WRNMMC point of contact will facilitate such approval. By entering into the Agreement, WRNMMC does not directly or indirectly endorse any opinions or facts stated in any report, thesis, presentation, or publication made by any Walden University students or faculty. The Program participants, including students, faculty and Walden University administrators, shall not in any way imply that this Agreement constitutes a WRNMMC or Government endorsement of any such opinions or facts presented in any fashion.

(4) WRNMMC, Walden University, and participating students and faculty agree to confer and consult with each other before publication or other public disclosure of the results of work under this Agreement to ensure that no proprietary information or military critical technology is released. Furthermore, before submitting a report, thesis or manuscript for publication or before any public disclosure, each party will offer the other party an opportunity to review such proposed report, thesis, publication, or disclosure, to submit objections, and to file pre-public disclosure patent applications in a timely manner, but in any case such review shall not delay release of publication for more than 45 days from submission. For patents related to and arising under this Agreement, Walden University shall grant the U.S. Government a non-exclusive, irrevocable, paid-up license in perpetuity.

(5) Walden University will inform participating faculty and students regarding the requirement to comply with WRNMMC policies and procedures. In particular, Walden

University must ensure that faculty and students receive health examinations and such other medical examinations and protective measures as deemed necessary by WRNMMC. Walden University faculty and students must understand that parking on the Naval Support Activity-Bethesda, where WRNMMC is located, is extremely limited, and public transportation is highly encouraged. Should Walden University faculty or students operate an automobile on the military base, they must maintain the minimum Maryland requirements for automobile liability insurance.

5. Funding: Each Party will be responsible for its own funding.

6. Representations:

   a. Of WRNMMC: WRNMMC hereby represents to Walden University that the performance of the activities specified by this Agreement is consistent with the mission of WRNMMC, and that the official executing this Agreement is authorized to do so.

   b. Of Walden University: Walden University hereby represents to WRNMMC that, as of the date hereof, it is an accredited educational institution under the definition of, and as required by 10 U.S.C. 2194, dedicated to improving science, mathematics, and engineering education; and that it has the requisite power and authority to enter into this Agreement and to perform according to the terms thereof.

7. Conditions and liabilities: The following conditions and liabilities will apply to this program.

   a. Walden University students and faculty will abide by WRNMMC rules for security, safety, and general conduct while at WRNMMC.

   b. Walden University students and faculty participating in the Program will be required to obtain security clearances to gain access to WRNMMC and its laboratories. Different levels of security are required depending on the access needs of the student. Students working at WRNMMC without needing to access the hospital computer network generally require a lower level of security. If the WRNMMC staff member overseeing the particular project requires that the student be able to access the WRNMMC network, a more extensive background check will be necessary. Obtaining the proper security clearance can take up to several months and will be the responsibility of the student and WRNMMC staff to coordinate. If work on projects requires Walden University student or faculty access to proprietary information in WRNMMC possession or information for which export is restricted, WRNMMC may allow work on the project on a case-by-case basis.

   c. WRNMMC Liabilities: WRNMMC's responsibility for injury or loss of property or personal injury or death caused by the negligent or wrongful act or omission of any employee of WRNMMC while acting within the scope of his office or employment will be in conformance with the Federal Tort Claims Act (28 U.S.C. Section 2671 et seq.). Except as provided by the Federal Tort Claims Act, WRNMMC shall not be liable to

Walden University or its faculty, administrators or students for any claims whatsoever, including loss of revenue or other indirect or consequential damages.

d. Walden University Liabilities:

Walden University will provide professional liability (malpractice) coverage, in amounts that are reasonable and customary in the community for the appropriate specialty, covering liability for personal injury or property damage, including legal representation and expense of defense of any such liability claims, actions or litigation, resulting from participation by Walden University's trainees and/or faculty under this agreement. This coverage may come from any source, but shall clearly cover the Walden University's faculty and trainees for any claim or lawsuit arising out of their participation at the DoD Facility, regardless of when the claim is actually filed. The source of this coverage shall be proven upon request of a Certificate of Insurance, and Walden University agrees that if it intends to change such liability coverage during the tenure of this agreement in a way that will affect the protection provided to their faculty and trainees, then Walden University will notify WRNMMC in writing, at least forty-five (45) days prior to the effective date of the change, specifying the changed intended to be made. The Walden University must provide documentary proof of the insurance coverage to the DoD Facility and such documentary proof will be attached to this agreement. Further, Walden University and their trainees and faculty further agree not to seek indemnification from either the United States or Department of Defense for any settlement, verdict or judgment resulting from any claim or lawsuit arising out of the performance of their trainee's or faculty's professional duties for their work pursuant to this agreement.

e. Walden University shall return all government-owned equipment, if loaned under this Agreement, to WRNMMC in good working order, normal wear and tear excepted, at the end of the time period(s) for loan or 30 days prior to end of this agreement, whichever comes first. While in the care or possession of Walden University, the equipment shall be covered by Walden University's insurance program. Any modifications or repairs to the government-owned equipment that the Walden University may find necessary to make shall be performed only after receiving written approval of the WRNMMC. Any such repair or modification shall be at the expense of Walden University and shall not affect the title of WRNMMC to said hardware and software.

8. Protection of personally identifiable and protected health information (PHI/PII): The Parties acknowledge that this Agreement lacks the requirements contained in a Health Insurance Portability and Accountability Act (HIPAA)-compliant Business Associate Agreement. As such, the parties acknowledge that the Walden University faculty and students participating at WRNMMC will be considered part of WRNMMC's workforce solely for purposes of PHI/PII access. Additionally, Walden University participants may only use/disclose PHI and PII consistent with the provisions of HIPAA and its implementing regulations and may not otherwise use/disclose PHI outside WRNMMC for any purpose.

9. Department of Research Program (DRP)/Institutional Review Board (IRB) Matters. The Parties will cooperate to ensure that any research projects involving Walden University

students are reviewed in accordance with applicable laws and regulations. Walden University students participating pursuant to this Agreement must complete and remain current on human subjects research training that the Parties require. WRNMMC calls this Collaborative Institutional Training Initiative or CITI training. Attached to this Agreement will be specific protocols (and any amendments). In addition, students may collect data from human subjects only under an institutionally-approved protocol. Both Walden University and WRNMMC have their own IRBs. The IRB approval process for a specific protocol will depend on the principal investigator of the work and the location of data collection. Before work is done on a protocol involving Walden University research students, the parties will collaborate to determine which IRB will review the project and which parties would need to be included in any research-related agreements, such as cooperative research and development agreements.

10. Administration: The administration of this Program and coordination of the activities that comprise the Program will be the joint responsibility of each Parties' designated program managers.

    a. WRNMMC POINT OF CONTACT: CDR (sel) Corey Carter, Assistant Service Chief Hematology/Oncology, Director of Clinical Research Hematology/Oncology. will serve as the point of contact on behalf of WRNMMC. He can be reached at 301-319-2104 or corey.a.carter.mil@mail.mil. If the WRNMMC point of contact becomes unavailable for continued service, WRNMMC will designate a successor point of contact and promptly notify Walden University.

    b. Walden University POINT OF CONTACT: Libby Munson will serve as the point of contact on behalf of Walden University. Walden University point of contact will coordinate Program activities with the WRNMMC point of contact and administrative requirements of Walden University. If Walden University point of contact becomes unavailable for continued service, Walden University will designate a successor point of contact and promptly notify WRNMMC.

11. General provisions:

    a. Entire Agreement: This Agreement constitutes the entire agreement between the Parties concerning the subject matter hereof and supersedes any prior understanding or written or oral agreement relative to this matter.

    b. Governing Laws: The laws of the United States of America as applied by the Federal Courts shall govern this Agreement for all purposes.

    c. Termination by Mutual Consent and Unilateral Termination: Walden University and WRNMMC may elect to terminate this Agreement at any time by mutual consent. Either Party may unilaterally terminate this entire Agreement at any time by giving the other Party written notice not less than thirty (30) days before the desired termination date. In the event of mutual or unilateral termination, the Parties shall specify the disposition of all activities accomplished or in progress, arising from or performed under this

Agreement, and they shall specify the disposal of all property in a manner consistent with this Agreement, and property disposal laws and regulations.

d. Period of Agreement: This Agreement will remain in effect for sixty (60) months unless previously terminated. At the conclusion of this term it may be extended by mutual written agreement of the Parties. Modifications can be made at any time by prior written mutual agreement of the Parties signed by authorized officials.

e. Surviving provisions: The articles covering Conditions and Liabilities, General Provisions and Surviving Provisions shall survive the termination of this Agreement.

Signatures:

For Walden University:

I, the undersigned, am duly authorized to bind Walden University to this Agreement and do so by affixing my signature hereto.

Entered into this 8 day of 4 (month) 2015 (year),

By: Dr Laura Lynn PhD
Dr. Laura Lynn, Ph.D.

Title: Executive Director of the Center for Research Quality

For WRNMMC:

I, the undersigned, am duly authorized to bind the Walter Reed National Military Medical Center to this Agreement and do so by affixing my signature hereto.

Entered into this 9 day of Sep (month) 2015 (year),

By:
Brian M. Belson, COL, USA, MC

Title: Director, Education, Training, and Research

Appendix B: Permission Letter

25 September 2013

Wanda C. Richards
[redacted]

Kimberly S. Johnson, MD
Duke University Medical Center
Division of Geriatrics
[redacted]

Dr. K. Johnson,

Good evening, my name is Wanda Richards; I am a Ph.D. student at Walden University School of Public Policy and Administration. My area of interest is the underutilization of hospice care in the African American veteran population exploring factors or barriers such as attitude and belief, distrust in the healthcare system, knowledge of hospice, and advance care planning. I have read several of your articles about hospice care and the one that I am particular interested in is "What explains racial differences in the use of advance directives and attitudes toward hospice care?" The instrument questionnaire that was used in your study, I would like to use it as well. Respectfully requesting permission to utilize this questionnaire in my study.

If you have any questions or concerns, please do not hesitate to send an email at captr04@yahoo.com or call [redacted]. Thanking you in advance for your consideration with assisting me to complete my education journey.

Sincerely,
Wanda C. Richards
Wanda C. Richards

You may use it.

Good luck

Kj

Kimberly S. Johnson MD
Associate Professor of Medicine

Sent from my iPad

On Sep 25, 2013, at 2:37 PM, “Wanda Richards” <captr04@yahoo.com> wrote:

Dear Dr. K. Johnson.

Good evening, my name is Wanda C. Richards and I am a Ph.D student at Walden University School of Public Policy and Administration, requesting permission to use your instrument questionnaire (see attached).

Peace and blessings,
Wanda

<Permission Letter-Dr. K Johnson.docx>

Appendix C: Survey

Protocol: 409107-1
Version date: 6 May 2015

Participant ID Number:______________________

Personal Information:

Thank you for agreeing to participate in the study. This first section contains some general questions about you and your health. Again this information will be kept confidential.

1. Race

_____a. African American

_____b. European American, Non-Hispanic

2. Gender

_____a. Male

_____b. Female

3. How old are you? ______

4. What is your current marital status?

_____a. Single, never married

_____b. Married

_____c. Separated

_____d. Divorced

_____e. Widowed

5. Do you have living children?

_____ Yes (If yes, how many? ______)

_____ No

6. What is the highest level of education you completed?

_____a. Less than high school

_____b. High school graduated or GED

_____c. Some college or technical training beyond high school

_____d. College graduate

_____e. Post-graduate or professional degree

7. In general, how would you rate your health right now?

_____a. Excellent health

_____b. Very good health

_____c. Good health

_____d. Fair health

_____e. Poor health

8. How many times in the last 12 months have you received services for yourself at an emergency room?

____

9. How many overnight stays have you had in a hospital over the last 12 months?

____

(This refers to the number of different times the patient has been admitted to hospital)

10. Do you have a diagnosis of cancer other than skin cancer?

_____a. No
_____b. Yes _____________ (type)

11. Do you have a diagnosis of terminal illness other than cancer?

_____a. No

_____b. Yes _____________(what)

12. A living will or advance care plan is a written document that states the kind of medical care you would want if you could not speak for yourself. Do you have a living will or advance care plan?

_____a. No (Go to 12b)

_____b. Yes (Go to 13)

12b. Have you ever heard of a living will or advance care plan?

_____a. No

_____b. Yes

13. A Durable Power of Attorney for Health Care or a Health Care Power of Attorney is a written document naming a person to make medical decisions for you if you are unable to make decisions for yourself. Do you have a Durable Power of Attorney for Health Care?

_____a. No (Go to 13b)

_____b. Yes (Go to 14)

13b. Have you ever heard of a Durable Power of Attorney?

_____a. No

_____b. Yes

14. Do you consider yourself…

_____a. Very religious/spiritual
_____b. Somewhat religious/spiritual

_____c. Not very religious/spiritual

_____d. Not at all religious/spiritual

15. How often do you attend church or other religious meetings?

_____a. More than once a day

_____b. Daily

_____c. Once a week

_____d. Two or more times/week

_____e. Few times a month

_____f. Rarely or never

16. How often do you spend time in private religious activities, such as prayer, meditation, or Bible study?

_____a. More than once a day

_____b. Daily

_____c. Once a week

_____d. Two or more times/week

_____e. A few times a month

_____f. Rarely or never

Hospice

This section contains questions and statements about hospice. Hospice is a program that provides care to people with illnesses that cannot be cured when they are at the end of their lives. The goal of hospice care is to keep terminally ill patients as comfortable as possible.

1. Have you ever heard of hospice?
   _____I have never heard of hospice.

   _____I have heard a little about hospice

_____I have heard a lot about hospice.

2. How did you learn about hospice services

_____I know someone who used hospice services.
_____I have used hospice services myself.
_____I heard about hospice from the radio, television, or newspaper.
_____I heard about hospice from my pastor.
_____I heard about hospice from others.

Remember, I am interested in your thoughts and feelings. These questions have nothing to do with your current state of health.

For the next set of statements about hospice, you should respond as follows depending on how much you agree or disagree with the statement.

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree

______1. If I were dying, I would want hospice care.

_____ 2. Even if I wanted hospice care, I could not afford hospice.

_____ 3. I wouldn't need hospice if I were dying because my family would take care of me.

_____ 4. Hospice is a place where people go to die.

_____ 5. Hospice care means you get no treatment.

_____ 6. Hospice treatment is not as good as treatment in the hospital.

_____ 7. Hospice care means giving up.

_____ 8. Hospice care causes people to die before their time.

Some questions taken or modified from Hospice Barriers Scale and the End-of-Life Care Survey.

Beliefs About Dying, Truth Telling, and Advance Care Planning

This next section asks about your views on death and dying. Again, these questions have nothing to do with your current state of health. I am simply interested in your thoughts and feelings.

You should respond to the statements as follows depending on how much you agree or disagree with the statement.

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree

_____ 1. I feel comfortable talking about death.

_____ 2. If I were dying, I would want the doctors to tell me.

_____ 3. If I were dying, I would tell my family.

_____ 4. Dying is a normal part of life.

_____ 5. Death should be avoided at all costs.

_____ 6. I have thought about the kind of medical care that I want when I am dying.

_____ 7. I have talked to my family about the kind of medical care that I want when I am dying.

Some questions taken or modified from Reese's Hospice Barriers Scale and the End-of-Life Care Survey.

Preferences for Care

Now I am going to ask you some questions about the kind of medical care you would want living with a disease, like cancer, that could not be cured. Again, these questions have nothing to do with your current state of health. I am simply interested in your thoughts and feelings.

You should respond to the statements as follows depending on how much you agree or disagree with the statement.

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree

If a disease (like cancer) that the doctors could not cure, I would want to live as long as possible,

_____ 1. even if I had to be on life support or a breathing machine.

_____ 2. even if my brain had stopped working.

_____ 3. even if I had to be fed through a tube

_____ 4. even if I were in severe pain.

If a disease (like cancer) that could not be cured,

_____ 5. being comfortable would be more important to me than living as long as possible.

_____ 6. being out of pain would be more important to me than living as long as possible.

_____ 7. being at home would be more important to me than being in the hospital.

_____ 8. and I could be taken care of at home, I would still want to go to the hospital or the emergency room.

Preference for Place of Death

If you were seriously ill with a disease like cancer that could not be cured and you could choose where to die, where would you most want to die?

_____ Home

_____ Hospital

_____ Nursing Home

_____ Other ___________________________

Some questions taken or modified from Hospice Values Scale and the End-of-Life Care Survey.

Trust:

The next questions are about your opinion of the health care system in general. When I refer to the health care system, I mean hospitals, providers, health insurance companies, and medical research. Remember your responses are confidential. I will not share your responses with your doctor and your responses will not affect your medical care.

Again, you should respond to the statements as follows depending on how much you agree or disagree with the statement.

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree

_____ 1. Medical experiments can be done on me without my knowing about it.

_____ 2. My medical records are kept private.

_____ 3. People die every day because of mistakes by the health care system.

_____ 4. When they take my blood, they do tests they don’t tell me about.

_____ 5. If a mistake were made in my health care, the health care system would try to hide it from me.

_____ 6. People can get access to my medical records without my approval.

_____ 7. The health care system cares more about holding costs down than it does about doing what is needed for my health.

_____ 8. I receive high-quality medical care from the health care system.

_____ 9. The health care system puts my medical needs above all other considerations when treating my medical problems.

_____ 10. Some medicines have things in them that they don’t tell you about.

All questions were taken from the Healthcare System Distrust Scale.

Spirituality:

This section contains statements about your religious or spiritual beliefs. Again, this information will be kept confidential.

As before, you should respond to the statements as follows depending on how much you agree or disagree with the statement.

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree

_____ 1. God determines whether you live or die.

_____ 2. Pain and suffering is sometimes part of God’s plan for my life.

_____ 3. God sometimes wants us to suffer while we are dying.

_____ 4. Those who believe in God do not have to plan for the kind of medical care they want when they are dying.

_____ 5. Those who believe in God would want everything done to keep them alive even if they had a disease like cancer that could not be cured.

_____ 6. Accepting that you are going to die means you do not have faith.

_____ 7. Those who believe in God do not need hospice.

Some questions taken or modified from Hospice Barriers Scale and the End-of-Life Care Survey.

Appendix D: Title: Factors That Contribute to the Underutilization of Hospice Care in the African American Military Beneficiary Population

Data Collection Sheet

Demographic Information

ID Number_____________

1. Race/Ethnicity:

______African American
______European American, Non-Hispanic

2. Gender:

_____Male
_____Female

3. Age______

4. Marital Status:

_____Single, never married
_____Married
_____Separated
_____Divorced
_____Widowed

5. Living Children:

______Yes, how many? ______
______No

6. Level of Education:

______less than high school
______High school graduate or GED
______Some college or technical training beyond high school

______College graduate
______Post-graduate or professional degree

7. Rate your health:

_____Excellent health
_____Very good health
_____Good health
_____Fair health
_____Poor health

Variable: Hospice Care	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Comments
1. If I were dying, I would want hospice care.						
2. Even if I wanted hospice care, I could not afford hospice.						
3. I wouldn't need hospice if I were dying b/c my family would take care of me.						
4. Hospice is a place where people go to die.						
5. Hospice care means you get no tx.						
6. Hospice tx. is not as good as tx. in the hospital.						
7. Hospice care means giving up.						
8. Hospice care causes people to die before their time.						

Variable: Beliefs and	Strongly Agree	Agree	Neither Agree	Disagree	Strongly Disagree	Comments

Attitudes			nor Disagree			
1. I feel comfortable talking about death.						
2. If I were dying, I would want the doctors to tell me.						
3. If I were dying, I would tell my family.						
4. Dying is a normal part of life.						
5. Death should be avoided at all costs						
6. I have thought about the kind of medical care that I want when I am dying.						
7. I have talked to my family about the kind of medical care that I want when I am dying.						

Variable: Trust in the Healthcare System	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Comments
1.Medical experiments can be done on me without my knowing about it.						
2. My medical records are kept private.						
3. People die every day b/c of mistakes by the health care system.						
4. When they						

take my blood, they do tests they don't tell me about.						
5. If a mistake were made in my health care, the health care system would try to hide it from me.						
6. People can get access to my medical records without my approval.						
7. The health care system cares more about holding costs down than it does about doing what is needed for my health.						
8. I received high-quality medical care from the health care system.						
9. The health care system puts my medical needs above all other considerations when treating my medical problems.						
10.Some medicines have things in them that they don't tell you about.						

Variable: Advance Care Plan	Yes	No	Type	What	Comments
1. Do you have a diagnosis of cancer other than skin cancer?					

2. Do you have a diagnosis of terminal illness other than cancer?					
3. Do you have a living will or advance care plan?					
4. Have you ever heard of a living will or advance care plan?					
5. Do you have a durable power of attorney for health care?					
6. Have you ever heard of a durable power of attorney?					

Appendix E: Consent Form

WALTER REED NATIONAL MILITARY MEDICAL CENTER (WRNMMC)
RESEARCH INFORMATION SHEET

Finding better ways to care for critically ill and injured patients is part of the mission of Walter Reed National Military Medical Center. Research is done to find ways to better care for patients like you who may be hurt or sick. To be sure your rights and welfare are protected while taking part, an institutional review board made up of other doctors, nurses and non-medical people from the community reviews all studies to ensure they are appropriate and any risk is minimized.

Title of Study: Factors That Contribute to the Underuse of Hospice Care in the African American Military Beneficiary Population

Study Investigator: CAPT(Ret) Wanda C. Richards, Doctoral Student, Walden University, Staff Education and Faculty Development, WRNMMC, [redacted]

What is the Purpose of the Study? The purpose of this study will be to evaluate the factors associated with the underutilization of hospice care in a terminally diagnosed, African American, military beneficiaries population. The result of this study will promote awareness about hospice care in the healthcare arena and to examine if there are cultural values, attitudes and beliefs in the African Americans military veterans culture ages 18-64 years that are not in harmony with the hospice's mission.

Why was I Selected to Participate? You are being asked to participate in this research study because you are diagnosed with a terminal illness and do not currently participate in hospice care. Taking part in this study is voluntary. You may choose either to take part or not to part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you and you not lose any of your benefits to which you are otherwise entitled. Leaving the study will not affect your medical care. Please read the information below, and ask questions about anything you do not understand, before deciding whether to take part in the study. You are one of up to 50 subjects being included in this research project.

What is Done in the Study? If you agree to be in the study, you will be asked to complete the End-of-Life Care survey. The survey asks for some personal information, such as race, gender, age, marital status, and questions related to your thoughts and feelings about hospice, death and dying, preferences for care, and healthcare system personnel. You will be asked to complete the End-of-Life Care survey on a laptop that will be available to use while you are in clinic. The researcher will be on hand to answer any concerns or questions. WRNMMC Chief Information Management Officer approved the use of a laptop device that can be utilized for this research. The survey will take about

30-45 minutes to complete.Your participation in the research will be over after you complete the survey.

Are There Any Risks or Discomforts? There is no expected risk, but at any time if something in this study makes the individual uncomfortable or upset, the individual may choose to stop taking part at any time without loss of medical care or benefits.

Are There Any Benefits to Being In This Study? The information from this study will assist military beneficiary population to have the knowledge that would be useful when making a decision about the use of hospice care.

Who Will See the Research Records and Survey Results? CAPT (Ret) Wanda C. Richards, Statistician, and Walden's IRB.

Research records of your participation in this study may only be disclosed in accordance with federal law, including the Federal Privacy Act, 5 U.S.C. 552a, and its implementing regulations. DD Form 2005, Privacy Act Statement – Military Health Records, contains the Privacy Act Statement for the records. In addition, The Health Insurance Portability & Accountability Act of 1996, Public Law 104-109 (also known as HIPAA), establishes privacy standards to protect your health information. The disclosure of your protected health information is necessary in order to be able to do this research project. It is the minimum necessary to do the research. By agreeing to be a part of this study, you agree to allow your protected health information to be used for this research. The records of your information will be destroyed three years after the research is finished. During the study, you will not be able to access your research records because it is important to make sure the results are reliable. Your authorization does not expire.

Information gained from your participation in this study may be published in medical literature, discussed for educational purposes, and used generally to further medical science. You will not be personally identified; all information will be presented as anonymous data.

The research records may be reviewed by the WRNMMC Institutional Review Board and other U.S. government agencies.

What If I Don't Want to Participate? Your decision to allow the information collected from you to be used in this study is completely voluntary. You may withdraw this consent at any time and discontinue further participation in this study without affecting your eligibility for care or any other benefits to which you are entitled. This would include, at your option, destroying any data already collected about you. Should you choose to withdraw, you must notify the Principal Investigator. Your condition will continue to be treated in accordance with acceptable standards of medical treatment.

With Whom Can I Talk If I Have Any Questions? The Principal Investigator or a member of the Office of the Institutional Review Board will be available to answer any questions concerning procedures throughout this study.

<u>Principal Investigator</u>: CAPT (Ret) Wanda C. Richards, Doctoral Student, Walden University, Staff Education and Faculty Development, WRNMMC, Phone Number: CAPT (Ret) W. Richards: [redacted]

<u>Department of Research Programs:</u>
Phone Number: [redacted]