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A Qualitative Study of Elderly Black Americans' Perceptions About Advance Directives

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A QUALITATIVE STUDY OF ELDERLY BLACK AMERICANS' PERCEPTIONS ABOUT ADVANCE DIRECTIVES

DISSERTATION

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Dale Ellen Flenyol

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by

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Abstract

Background: Elderly Black Americans have specific cultural knowledge and beliefs related to Advance Directives (ADs). ADs address issues pertaining to preplanned end-of-life care. Literature reviews support that the majority of Black Americans do not have ADs.

Purpose: The purpose of this study was to explore the perceptions of elderly Black Americans about ADs. The use of ADs has been advocated as a measure to help decrease health disparities in minority, under-served, under-represented members of society.

Philosophical Underpinnings: Qualitative inquiry methods were employed as the philosophical underpinnings as described by Miles and Huberman, Leininger, and van Manen

Methods: The philosophical underpinnings of this study arose from a naturalistic paradigm. One-on-one, face-to-face, audiotaped interviews between the researcher and a purposive group of nine participants were the primary source of data collection, supplemented by field notes and observations. The data were reduced and coded until themes emerged to describe elderly Black Americans' perceptions about ADs.

Results: The transcribed interviews were analyzed. Four major themes emerged: educational deficit, burdens financial/other, religiosity/spirituality, and a dominant overriding theme of avoidance. The researcher also identified sub-themes of trust/distrust, responsibility and social support, fatalism, and pain/discomfort.

Conclusion: Themes emerged that were consistent with prior literature. Elderly Black Americans continue to be underserved recipients of healthcare and do not sign nor have

knowledge of AD documents as compared to Whites. Nurses may use knowledge from this study as a template when issues arise from patients who are from “other” cultures.

ACKNOWLEDGMENTS

I acknowledge and graciously want to thank my Dissertation Committee Members, Dr. Sandra Walsh, Dr. Karen Thornton, and Dr. Jessie Colin. During the time I have spent at Barry University, Dr. Walsh has gone above and beyond to help me attain my lifelong goal. The qualitative approach to the dissertation “process” requires one to interact with people. I have developed relationships of a lifetime from these experiences. In saying that, I humble myself and acknowledge the participants belonging to a valued part of community, the elderly Black Americans who trusted, helped, and supported me by participating in this research study.

DEDICATION

I made a promise to my dear mother. I said: “Mommy, I am going to have a PhD before I am 65.”As I promised, I dedicate this to you Mommy for giving me the gift of determination to peruse my goal. Thank you Mommy; I made it.

Dear Dr. Walsh, I truly want to thank you for your time, effort, patience, and commitment necessary to make my dream come true. You are truly a dying breed in the academic community. You sit on a pedestal, on the solid ground of education. You maintain the rigor and exactness in educating others, without the politics, economics, and negativity associated with education today. From my heart, sincerely...

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CHAPTER ONE

Problem and Domain of Inquiry

Background of the Problem

Advance Directives (ADs) are documents that give patients a say in the way they choose to spend the last days of their lives and how they wish to die. There have been rapid advances in medical knowledge and expanding medical capabilities to extend physiological life at the end of life. These increased medical capabilities have also generated political, ethical, racial, moral, and religious conflicts in the delivery of ADs to assist persons with advance end-of-life care planning. Such planning is especially difficult for elderly Black Americans.

AD documents were created in 1991 stemming from the Patient Self-Determination Act (PSDA) enacted into law by the United States Congress. The PSDA was founded on the belief that every competent adult has the right to make decisions concerning end-of-life care. The PSDA ensures patients' rights to dignity, personal autonomy, and comfort in matters pertaining to their healthcare and end-of-life care (Doukas & Hardwig, 2003; Thrall & Hudson, 2005). ADs include specific information that includes a person's right to choose or to refuse medical treatment (Patient Self-Determination Act, 1991).

As people age, they may feel incompetent to make decisions about ADs (Decker & Reed, 2005). Additionally, a person may become incapacitated due to a physical or mental change resulting from a debilitating disease or disease progression at the end of life. At such time, previously initiated AD documents can guide healthcare workers and family members to make decisions for patients unable to speak for themselves (Decker & Reed, 2005).

An Aging Population

The PSDA and ADs have increasingly important because of the aging of the U. S. population. The U.S. Census Bureau (2002) reported that the 2000 Census was be the largest census in the history of the United States, counting over 281 million people. The U.S. Census Bureau (2000) projected that the older population would number 86.7 million when people born between 1946 and 1964 began in 2011 to turn 65 years old. (see Figures 1 and 2).

The older population is projected to increase from 36 million in 2003 to 72 million in 2030 (U.S. Census Bureau, 2000). The Black American population (or non-Hispanic Blacks) between the ages of 55 to 74 was reported as 12.3% (U.S. Census Bureau) with projections that parallel the projections of non-Hispanic Whites. However, the percentage of Black American sharply decreases after the age of 85 (U.S. Census Bureau, 2000). The United States Census Bureau (2003) reported that over the last 10 years, the mortality rate for African (Black) American adults in the United States has decreased by 19%. Also, life expectancy of African Americans has increased by 35.2%.

The Black American

Black American acculturation in this country is distinctly different from that of other cultures. Cultural differences occur in an aging Black population, along with changes in healthcare and cost containment within the healthcare system. Such issues prioritize the need for preplanned end-of-life healthcare planning for elderly Black Americans.

The ability to interact effectively with people of different cultures is called cultural competency(Martin & Vaughn, 2007). Cultural competency is needed as nurses or designated hospital staffs are required by the PSDA legislation to inquire at the time of admission if the patient has knowledge of ADs, has signed ADs, or has an interest in initiating ADs (Patient Self-Determination Act, 1991). Cultural competence is an ongoing process in which the nurse continuously strives to achieve the ability and the availability to work effectively within the cultural context of the patient (Campinha-Bacote, 2002). Johnson, Rolnick, Asche, and Heinrich (2009) have suggested that key elements to promote the initiation of ADs include a focus on ongoing culturally sensitive discussions of end-of-life care planning or wishes rather than on the completion of a single document.

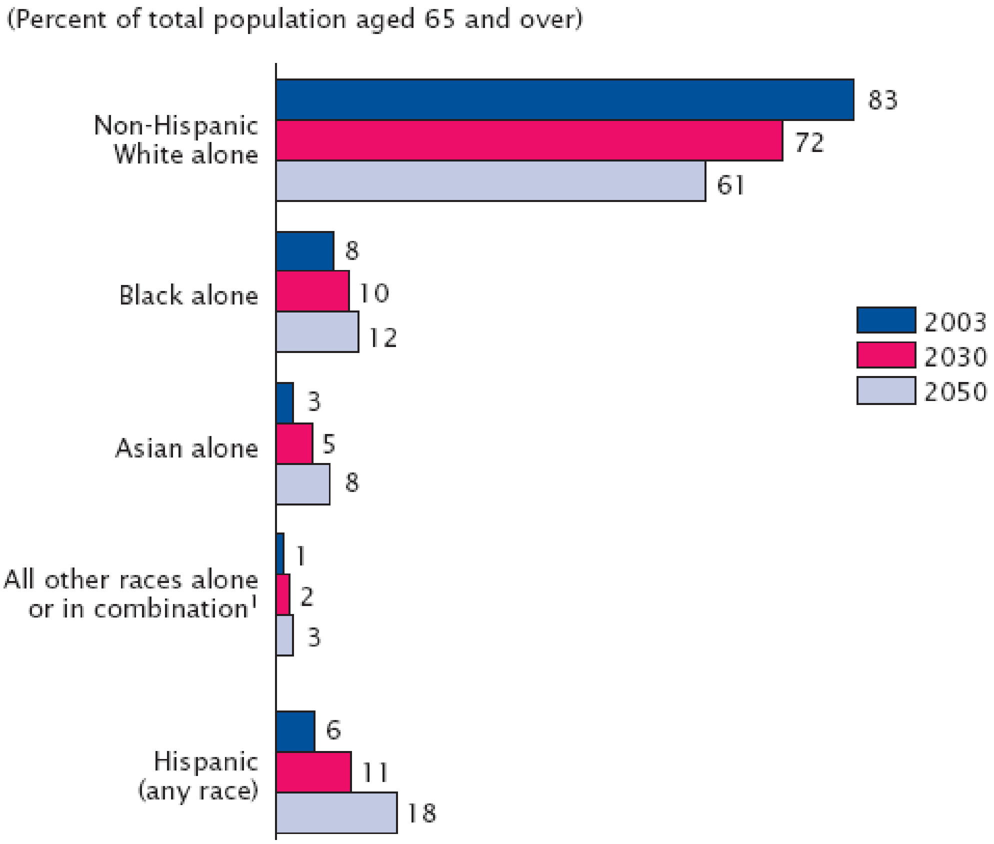


Figure 1.Projected percent of population aged 65 and over in 2010 (Healthy People 2010, U.S. Department of Health)

Population Distribution by Race/Ethnicity, states (2009-2010), U.S. (2010)

	FL #	FL %	FL % of US Total	US #	US %	US % of US Total
White	11,059,300	60%	6%	196,784,000	64%	100%
Black	2,790,500	15%	8%	37,024,600	12%	100%
Hispanic	3,922,200	21%	8%	49,881,300	16%	100%
Other	641,700	3%	3%	21,501,300	7%	100%
Total	18,413,600	100%	6%	305,191,100	100%	100%

Figure 2. Florida: Population distribution by race/ethnicity, states, 2009 -2010. Population by racial grouping. (Source: U.S. Census Bureau, current population survey: March 1999)

Cultural Identity

Cultural identity may determine what decisions people make about end-of-life care (Watts, 2003). The Black American population has specific ethnicities associated with their culture. Accordingly, folklore dictates the decision about the death process (Turner-Strong, 2005). Literature suggests that Black Americans convey that they prefer accept more life-prolonging treatments despite increased disability (Winter, Lawton, & Ruckdeschel, 2003). Race and rituals associated with their culture, as a determinant, are predominantly the most vital predictor of end-of-life treatment decisions (Winter, 2009).

Elderly Black Americans are highly respected within their culture. The stories of the “wise elders” was gospel, since the “elders” are the ones who held what was presumed to be true within the elderly Black American community. The process of storytelling to keep a culture alive was reinforced and a vital link to the culture of slaves, as slavery was introduced into this country. The tradition of “keeping history” is kept alive today by writing in Bibles or writing important information on paper and keeping it in the family bible.

Black American families revere the Bible as a strong object in their families. Slaves were not allowed to read and write. Slavery reduced an individual’s status and left slaves without power. The power of education was recognized by the slave owners and was a forbidden tool for the slaves to have. Even in slavery the power of education was threatening to the very foundation and structure of slavery. The researcher’s testimony can verify these facts. Slavery divided, segregated, and destroyed common groups and tribes’ cultural norms was introduced into this country. The influence of cultural identity is one determinant that influences the end-of-life care decision making for the elderly

Black American. Elderly Black Americans have specific beliefs, morals, and habits; their traditions dictate the decision making process about their death process. Turner-Strong (2005) and Shellman (2004) refer to the differing realities that exist within the same culture and the importance of healthcare professionals to be aware of those individual differences. Another reason for cultural consideration may be due to lack medical knowledge within Black communities (Barnett et al., 2007). Due to the lack of access to healthcare providers or other unknown cultural influences, elderly Black Americans may not have the opportunity to be introduced to or to make informed decisions about ADs.

Statement of the Problem

Black Americans are less likely to know about or to complete ADs despite the availability of such preplanned end-of-life care documents (Born et al., 2007: Caralis, Davis, & Wright, 1993; Eleazer, Hornung, & Egbert, 1996; Kiely, Mitchell, Marlow, Murphy, & Morris, 2001). Black Americans do not plan for end-of-life care, as they have limited knowledge and access to information about end-of-life health preplanned care (Welch, Teno, & Mor, 2005). The lack of education (Dupree, 2000; Hawthorne, Robles, Cannings-John, & Edwards, 2006), cultural beliefs (Shrank et al., 2005), and strong religious beliefs (Joseph, 1998; Rosenfeld, Wenger, & Kagawa-Singer, 2000; Wheeler, Ampadu, & Wangari, 2002) may contribute to the lack of completion of ADs by elderly Black Americans.

The lack of action by elderly Black Americans related to end-of-life planning highlights the need for nurses to provide culturally appropriate end-of-life care for them. Culturally appropriate healthcare seeks to be culturally comparable across populations or groups that share the same social behaviors, beliefs, assumptions about the world, and values (Williamson, & Harrison, 2010). If nurses are able to provide culturally appropriate preplanned end-of-life care, nurses, as patient advocates, may help resolve one of the health disparities related to such care for elderly Black Americans. Health literacy, economics, ethnicity, health disparities, and mistrust of the medical community continue to be issues in the initiation and implementation of ADs in the elderly Black American community (Bradley, 2005; Dupree, 2000; Waters, 2000). This study explored the perceptions of elderly Black Americans about ADs. Nursing practice, education, research, and public policy benefited from the knowledge. The ultimate goal of this research was to provide additional knowledge and perhaps help nurses promote desirable preplanned end-of-life and a dignified death for the elderly Black American population by initiation of some form of AD.

The use of ADs by elderly Black Americans and the decision making processes that surround end-of-life care have been a source of concern leading to controversy and debate (Fagerlin & Schneider, 2004). There are multiple problems associated with the initiation of ADs that may be related to health disparities of the elderly Black American population (Carlson & Chamberlain, 2004; Lane, Rubinstein, Cibula, & Webster, 2000). There is a substantial deficiency in the research on issues related to the implementation of preplanned end-of-life care planning and use of ADs in elderly Black Americans.

Purpose of the Study

The purpose of this study was to explore elderly Black Americans’ perceptions about ADs.

Definition and Key Terms

Race refers to the relationship between two or more humans interacting with one another based on various sets of genetic and environmental factors or characteristics (Bhui & Dinos, 2008). Culture refers to people living in different parts of the world who have and who are classified and represented by their experiences. Different cultural groups represent integrated patterns of human knowledge. Cultural groups share beliefs and behaviors that depend upon the capacity for symbolic thought and social learning. People of the same culture share the same attitudes, values, goals, and practices (White, 1943). Ethnicity refers to cultural factors such as ancestry, language nationality, culture, and beliefs. Traditionally ethnicity identified in terms of shared genealogy, whether actual or presumed. Example, if a person believes they descend from a particular group, and they want to be associated with that group, then they are in fact members of that group. People with the similar ethnicities/cultures, identify with each other through a common heritage (Spencer, 2006). Their heritage may be based on recognized common ancestry, history, kinship, religion, language, shared territory, nationality, or physical appearance. Others mark individuals of an ethnic group as such due to the group’s uniqueness (Bulmer, 1996).

The term “Black American” refers to an ethnic Black American. There are different classifications of the racial term Black around the world (Shelby, 2002). In this age of globalization, the term Black can vary from one context to the next depending on who is using the term. For example: this study focuses on the Black American population with cultural roots in America. The target population also have cultural roots in America and descendants from slaves in America. Caribbean people, Haitians, Cubans, and South Americans were excluded from the sample, because of the differences of ethnicities. The word “elderly” is a mandatory identifying factor for the proposed study to describe participants that are to be included in this study. Elderly is defined as persons 65 years of age and older. “Passing” is a term that is used to describe an individual’s death and is a commonplace colloquium used within the Black community. The word has the connotation of some spiritual connection. The passing of an individual also refers to the spirit leaving the body and entering a “higher” place. A higher place is a place in which the continuity of life after death and the spirit passes from one dimension of existence to another in the spiritual sense (Padgett, 1941). As described earlier, Advance Directives (ADs) are documents used an aid for patients to have a say in the way they choose to spend the last days of their lives and include a description of how the individual wishes to die.

Research Question

What are elderly Black Americans’ perceptions about Advance Directives (ADs)? To answer this research question, one major domain question followed by other specific questions (see Appendix F, labeled “Research Questions”) were posed to participants. Specific considerations regarding the process the researcher used to answer the research questions are discussed in Chapter Three.

Philosophical Underpinnings

The historical roots of qualitative research are found in the works of the German theologian Friedrich Schleiermacher (1768-1834). In the 17th century, Schleiermacher introduced hermeneutics as a sub-discipline of theology. Hermeneutics, which is also known as interpretive phenomenology, is a type of naturalistic inquiry (Tripp-Reimer &

Doebbeling, 2004). Hermeneutics was introduced as a method for biblical and classical literary interpretation (Eberhart & Pieper, 1994). Among the assumptions of hermeneutics are that humans experience the world through language and that language provides both understanding and knowledge (Byrne, 2001). Hermeneutics is also referred to as the "art of interpretation."

Assumptions

The German philosopher Wilhelm Dilthey (1833-1911) extended the interpretation of Schleiermacher's hermeneutics into the historical sphere to provide an epistemology for understanding human action (Schweiker, 1999). Heidegger (1962) effected the transition of hermeneutics from epistemology to ontology through the influence of Husserl (1965). "Being" is referenced as the ontological aspect of nature and reality. Reality is interpreted as believed by the individual participant. There are various realities of participants according to their individual interpretation of their relationship to the environment and the individuals' reality of the environment.

Heidegger viewed hermeneutics as a philosophical rather than a scientific method. Hermeneutics is the direct investigation and description of phenomena as experienced in life by using the practice of reflection and writing to understand the forms of life (van Manen, 1990). Heidegger and Hans-George Gadamer, another German philosopher, were decisive figures in hermeneutic analysis. Hermeneutics phenomenology has been connected to revealing otherwise concealed meanings in the phenomena (Streubert & Carpenter, 1999).

Hermeneutics has both descriptive and interpretive elements (Heidegger, 1962). Descriptive phenomenology involves direct exploration as free as possible from presuppositions aiming at maximum intuitive presentation. Interpretive phenomenology is valuable for the study of phenomena related to nursing education, research, and practice. Interpretive phenomenology is the interpretation of phenomena appearing in text or the written word (Streubert & Carpenter, 1999). Through a descriptive and an interpretive method, hermeneutics enlightens nursing practice because of its focus on the detailed description of an individual's experience in the world. Qualitative research offers the opportunity to focus on finding answers to questions centered on social experiences.

In the 1960s, largely due to the influence of sociology and social theory, the nursing profession became disenchanted with "care" as prescriptive, rigid, and measurable (Anderson, 1989; Lincoln & Guba, 1985; Morse, 1991; Sandelowski, 2000: Sandelowski, 1986; Sandelowski & Barroso, 2003; Sandelowski, Doeherty, & Emden, 1997; Streubert & Carpenter, 1999). Some nurses saw this logical-positivistic approach and the methodology associated with logical positivism as constraining and therefore looked to an alternative method of research as a way of investigating questions concerned with the lived experience of patients and their families (Cushing, 1994).

Qualitative research methods employ approaches used by social scientists and anthropologists to achieve an understanding of the meanings that human beings attach to their lives. Morse (1991) hypothesized that qualitative methods were introduced into nursing by nurses who had obtained experience in other disciplines, such as anthropology, ethnography, philosophy, and the social sciences. Anderson (1989) highlighted the arrival of phenomenology, a form of qualitative research that describes individuals through their lived experience, as a qualitative method.

The positivist-ontological view of how reality exists was replaced by the constructivist’s view of reality. The post positivists’ views supported the qualitative tradition for the most meaningful way to describe and understand reality, that is, that reality is dynamic, ever changing, and a necessary step to understanding a truly humanistic perspective of research (Streubert & Carpenter, 1999; Streubert, Speziale, & Carpenter, 2003). The Constructivist believes in order to understand this world of meaning, one must be able to interpret that world.

The researcher used a Constructivist approach to clarify what and how meanings are embodied in language. Constructions are extracted and refined only through interaction among the investigator and the participants. The aim is to extract a consensus construction that is more informed than previous constructions, including any previous interpretive constructions of the researcher.

The relationship between the participants, the researcher, and the knowledge that is developed is created or constructed. The participants and the researcher create an understanding about the construction of the final knowledge. The constructivist researcher uses a qualitative approach as a foundation for an interpretive and naturalistic approach. As the word "constructivist" symbolizes a fabrication of sorts, The constructivist's tradition is rich, deep, and complex as interpretation of their studies evolve and unfold (Lincoln & Guba, 1985).

Sandelowski (2000) is not a principal developer of qualitative inquiry. Her occupation within the field of qualitative research is rigor and credibility within the qualitative research process. (Sandelowski, 2004; Sandelowski & Barroso, 2003; Sandelowski, 2000; Sandelowski, 1986; Sandelowski et al., 1997). Sandelowski’s research into qualitative descriptive inquiry has enabled researchers to provide straight descriptions to phenomena and will be useful for researchers wanting to know who, what, and where of events. Through reconstruction, the researcher used naturalistic inquiry and applies inductive analytic approaches.

Naturalistic inquiry is used as a method to better understand characteristic patterns and structures to provide direction in the creation of an interpretive account generated by conclusions and the interpretation of questioning. Sandelowski (2000, 2004) used the phrase “qualitative description” to characterize designs aimed at obtaining minimally interpreted answers to real-world research questions. Qualitative-descriptive research is less theoretic, less philosophic, and more naturalistic than grounded theory, phenomenology, or hermeneutic designs. Sandelowski's method does modify the original naturalistic inquiry techniques described by Lincoln and Guba (1985) but still satisfies the steps necessary to qualify the paradigm as qualitative research.

Importance/Significance of the Study

The significance of this study was intended to promote the understanding of healthcare professionals about how elderly Black Americans perceive ADs. If information can be obtained from elderly Black Americans about their perceptions of ADs, the knowledge gained may affect the way healthcare information about ADs is delivered by healthcare professionals to elderly Black Americans. Although previous research has been conducted about end-of-life care, only one unpublished dissertation was found that specifically addressed issues related to Black Americans and ADs (Bradley, 2005). It was hoped that the research findings would enhance Bradley’s study and address the gap in knowledge about elderly Black Americans and their perceptions of ADs.

The qualitative approach to discuss the perceptions of elderly Black Americans about ADs was used to address the needs of the nursing profession and the concerns of the researcher as a Black American scientist. The goal of this qualitative proposal was to enhance the base of nursing knowledge by increasing information related to elderly Black Americans' perceptions about ADs and their end-of-life care. As an anesthetist, a nurse, and a Black American, the researcher wanted to inform herself about the reasons for the use or the lack of use of ADs by elderly Black Americans for their end-of-life care. Such an approach may be one means to help decrease health disparities in the elderly Black American population. The intent of the research was in accordance with the *Healthy People 2010* initiatives to decrease health disparities of vulnerable groups (U.S. Department of Health and Human Services, 2002).

ADs are documents that require understanding of written English and health matters by someone who might consider signing such documents. If Black Americans are not health literate, they are unlikely either to understand or to consider signing such documents. Therefore, the issue of health literacy may be a major factor to understand as health personnel discuss end-of-life concerns with elderly Black Americans (Williams, 2006).

The issue of health literacy is included in *Healthy People 2010* initiatives (U.S. Department of Health and Human Services, 2002). When a person has acquired the basic skills required to comprehend the use of information to make decisions about health, he or she is health literate, according to *Healthy People 2010*. Unfortunately, these basic skills are absent in more than half of the U.S. population. More importantly, these are the same skills associated with improved quality of life and longer life, a reduction of chronic disease and health disparities, and savings in medical-care lost dollars (*Healthy People 2010*). The absence of health literacy is more disturbing when one considers that reading, comprehending, and being exposed to basic health information are the very skills and strategies that often lead to longer life, improved quality of life, reduction of both chronic disease and health disparities, and cost savings (see Figure 3).

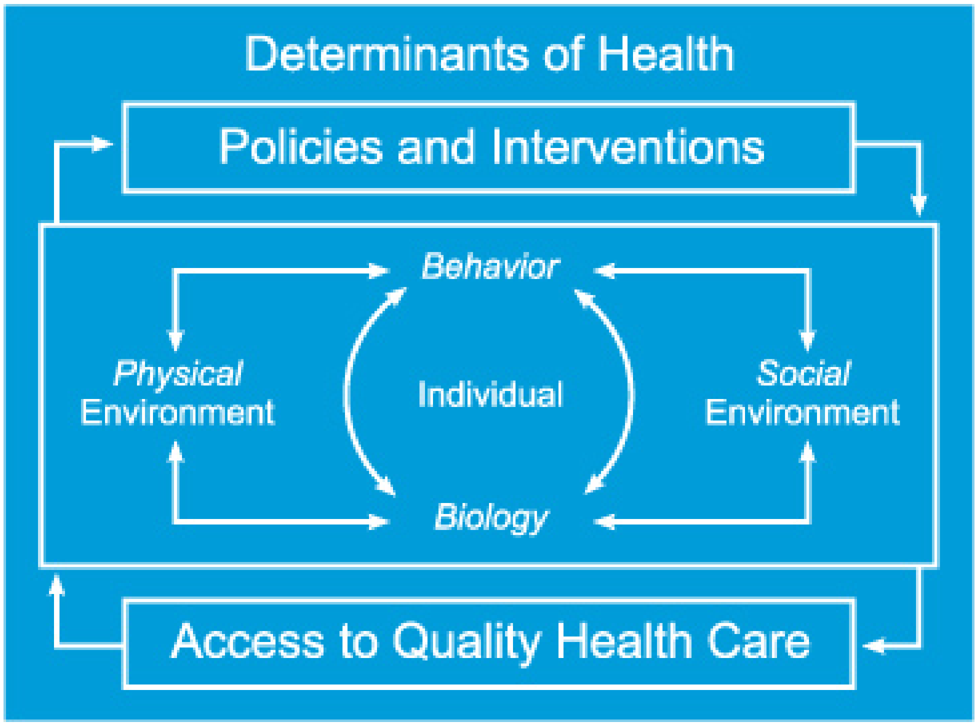


Figure 3.Critical influences that determine health of individuals. Source: U.S. Department of Health, Healthy People 2010 (2000).

The significance of this study is that by exploring elderly Black Americans' perceptions about ADs, strategies for health professionals may be designed to promote health literacy. Perhaps educational materials can be developed and used by healthcare personnel for audiences with limited literacy. The federal government has designed documents that provide the necessary materials to develop strategies to provide quality of life at the end of life. However, no such materials are yet available to assist elderly Black Americans in considering and understanding AD documents.

Significance to Nursing

This study increased nurses' knowledge about how to render quality end-of-life care to the elderly Black American. Nurses can now be equipped with adequate tools and know what elderly Black Americans do and do not want at the end of life or how to ask them about their wishes about their quality of life at the end of life. Findings were expected to augment the knowledge and have the potential to change the way healthcare information about ADs is delivered to elderly Black Americans by healthcare professionals.

If an elderly Black American can be encouraged to discuss end-of-life care with a nurse perceptions a nurse may be better equipped to aid the patient to pass into the end-of-life stage with dignity, harmony, and peace. Helping others come to peace at the end of life was rated as having greater importance to patients than to physicians (Steinha et al., 2000). Recognition of the need for end-of-life care, including knowledge about a patient's end-of-life care wishes, was the focus of the Fifth International Consensus Conference in Critical Care (Thompson, 2004). The statement focused on respecting the patient's autonomy while providing end-of-life-care. When ill health or a change in social circumstances disrupts an older person’s life, nurses could utilize information from knowledge about elderly Black Americans’ perceptions of ADs to discuss cultural and individual end-of-life care of the patient and their support systems.

Education

Kuczmarski and Cole (1999) have suggested that self-awareness is a critical indicator of success for cultural competence. Because of findings from this study, nursing students and nurse clinicians may become more sensitive in their verbal and nonverbal communication about AD materials to elderly Black Americans. When persons were asked about dying, the most important request was improved communication regarding end-of-life choices, including issues about ADs (Gallo, Straton, & Klag, 2003).

New knowledge from elderly Black Americans’ perceptions about ADs can be integrated throughout nursing curricula at every level of nursing education. Enhanced nursing education related to ADs could benefit evidence-based diversity education and theory-guided research. Nurses armed with additional knowledge about elderly Black Americans’ perceptions about ADs may significantly improve the quality of end-of-life care. Increasing end-of-life care knowledge about elderly Black Americans may serve to solidify nursing as a unique discipline and to foster excellence in caring for this population at the end of life.

Practice

The nurse is often the first person that a patient or family encounters when confronted about issues on end-of-life care plans (Bradley, 2005). New knowledge about elderly Black Americans’ perceptions about ADs could provide nurses in clinical practice with the ability to effectively facilitate an awareness and implementation of ADs for elderly Black Americans. Nurses in clinical practice are in positions to promote health literacy, specifically presenting culturally appropriate information about ADs to elderly Black Americans. Knowledge provided by this study may assist nurses to evaluate their own perceptions about a patient's decisions regarding end-of-life issues and ADs. The knowledge that a nurse needs to communicate adequately with the elderly Black American about ADs extends to the patient's family and/or support systems and to the patient's cultural orientation.

Research

Leininger (2002) predicted that qualitative methods will dominate nursing research in the 21st century because of these methods will gave meaning to covert, unknown, and important phenomena, especially in the field of healthcare. From the outcomes of this qualitative study, nurses may be better able to understand the needs of elderly Black Americans. Specifically, researchers may further understand elderly Black Americans' perceptions about ADs. The investigation of elderly Black Americans' perceptions about ADs may uncover a new research direction, with added focus on the group's cultural values and beliefs. The study may uncover up-to-date information to promote new research to investigate cultural awareness as nurses address end-of-life care issues with elderly Black Americans.

Exploring elderly Black Americans' perceptions about ADs may aid nurses in offering culturally appropriate end-of-life information to patients. New educational materials and/or interventions may be developed and tested as knowledge from the proposed research is disseminated (Fawcett, 2002). The addition of culturally specific educational models to introduce ADs to elderly Black Americans could guide future research investigations.

Health/Public Policy

Providing the best possible care is the responsibility of the healthcare institution and the community it serves. Rectification of end-of-life care issues addressed at the public-policy level may highlight end-of-life care challenges and may provide new solutions for ethical committees, families, and the judicial system. Not addressing issues related to ADs costs healthcare institutions additional dollars and cause undue pain and suffering for the individual and significant others (Fernandez-Lynch, Mathes, & Sawicki, 2008;Smith, 2005). The concept of participation by individuals in promoting advance end-of-life planning has been a foundation of public policy instituted in Sweden, the United Kingdom, and other countries (Wilde, Starrin, Larsson, & Larsson, 1993). The findings from this study provided new knowledge to promote increased initiation of ADs, or at least, to foster improved communication about end-of-life care among policy makers in the United States.

The goal of the legislation in the current PSDA is to maximize patients' rights to self-determination regarding healthcare decisions. The PSDA was enacted to protect healthcare providers and those who make decisions for incompetent patients from liability and to increase the preparation and use of ADs (High, 1991). Although the goal of the PSDA was to increase the use of ADs, an individual's right not to complete one is part of upholding the self-determination law (Patient Self-Determination Act, 1991). The direction of the legislation and public policy is to uphold a patient's autonomy without fear of caregiver prosecution due to existing laws (Sieger, Arnold, & Abronheim, 2002).

As the literature suggests, factors influencing an individual's decision to formulate directives are multifaceted and complex. The research for this study may discover knowledge that contributes to policy/legislation on the preferences of elderly Black Americans concerning ADs. Perhaps as a part of nursing-care policy planning, improving the delivery and the execution of ADs will emphasize nurses' commitment to the patient and to patient empowerment (Perkins, Geppert, Gonzales, Cortez, & Hazuda, 2002). The dynamics involved in making end-of-life decisions range from large-scale policy on how and when information on ADs is presented to patients to considerations of perceived advantages and disadvantages of formulating ADs (Moore & Sherman, 1999).

Scope and Limitations of the Study

Although the study focused on elderly Black Americans, the diversity within the Black race far exceeds that of the culture of the elderly Black Americans who participated in this study. Study participants were limited to persons who were native Black Americans; persons from other cultures, such as Caribbean, Haitian, Cuban, Dominican, and Puerto Rican, were excluded. Cutcliffe (1999) discussed limitations in attaining data saturation and the possibility for further investigation to test the conceptual ideas for major pitfalls of credibility in qualitative research. Since some Black Americans feel excluded from certain health services due to their race (Blackford, 2003), those persons may not choose to volunteer for inclusion in a research study. The trust or lack of trust that was being established between the researcher and the participants during the one-on-one, face-to-face interviews was strength and not a limitation for the study. The researcher feels that the use of a purposive, volunteer sample did not affect outcomes.

Despite its new prominence in the practice disciplines, concerns remain about the ability of qualitative research to resolve “real-world” problems. Debates between qualitative and quantitative researchers continue regarding the usefulness of exploratory qualitative approach. In qualitative approaches, there remains a relative absence of effort to integrate, synthesize, or otherwise put together the findings from descriptive exploratory qualitative investigations (Sandelowski & Barroso, 2003).

The scope of this research, in the future, could be extensive due to the large and growing population of elderly Black Americans in this country who eventually will face end-of-life decisions. Either the initiation of an AD or finding the reasons for refusal to complete an AD may uncover knowledge that has the potential to provide better end-of-life care for the elderly Black American. As important as it may be to discover factors associated with the initiation of ADs, it may be just as important to discover the reasons elderly Black Americans refuse to initiate them. Elderly Black Americans’ perceptions about ADs may uncover knowledge needed by health professionals, specifically nurses.

Not everyone is an advocate of the initiation of ADs. Fagerlin and Schneider (2004) conducted research that contends that ADs have failed and that ADs should be abolished. They concluded that the evidence to support the failure of ADs is the fact that so many patients do not have them. Although Fagerlin and Schnieder are pessimistic about ADs, they advocate more detailed and explanatory AD documents better tailored to a patient’s individual needs. Pekmezaris et al. (2004) express the same opinion in their research. Participants in this research may offer ideas about individual approaches to ADs for elderly Black Americans.

Chapter Summary

The background of ADs and the purpose of the study were explored. Elderly Black Americans’ perceptions about ADs were discussed in relation to the enactment of the PSDA. The PSDA is a law to ensure patients’ rights to dignity, personal autonomy, and comfort in matters pertaining to their healthcare, including matters pertaining to end-of-life care (Doukas & Hardwig, 2003; Thrall & Hudson, 2005). Elderly Black Americans may feel hesitant about ADs; they may not have access to ADs; or they may be unable to make decisions about ADs (Degenholtz, Arnold, Meisel, & Lave, 2002; Perkins et al., 2002). The research focused on elderly Black Americans’ perceptions about initiating or not initiating ADs. The researcher hoped that the knowledge gained will broaden the ability of nurses to deliver culturally appropriate advance-care planning to the elderly Black American through changes in education, clinical practice, research, and public policy.

CHAPTER TWO

Review of the Literature

Introduction/Overview

The purpose of this study was to explore elderly Black Americans' perceptions about ADs. Black Americans do not plan for end-of-life care, as they have limited knowledge and access to information about end-of-life health preplanned care (Welch et al., 2005).Search words for the literature review focused on Black Americans, culture, ADs, racial bias, and end-of-life care. Computer search engines used were: MyLibraryService.org, EBSCO, Academic Search Premier Plus, CINAHL, PsycArticles, Dissertation Abstracts Online, Blackwell Medicine Collection, Pub Med, and the Barry University's online search engines. The review of the literature was limited to material during the years of 1999 to 2010 unless material was seminal and/or relevant for the study.

African Americans complete ADs at a much lower rate than other ethnic groups (Bullock, 2006). Access to medical care by Black Americans has become a national research priority. The use of ADs by elderly Black Americans is included as one of those factors. The use or lack of use of ADs was not identified as a limiting factor of access to appropriate end-of-life care for the elderly Black American. Race influences attitudes about advance care directives and preference for end-of-life care (Mebane, Oman, Kroonen, & Goldstein, 1999). Additionally, ADs are one of the strategies that health professionals may use to help decrease health disparities, especially for the elderly Black American (U.S. Census Bureau 2000, 2002). Education on end-of life care issues including the understanding of and use of ADs affected factors associated with perceptions of elderly black Americans about ADs.

Historical Context

Dittmer (1995) examined the reasons why so much confusion surrounds the interpretation of the Black American culture. He examined the dominating variants between the European-American and Black American cultures as though they existed on the same cultural level. He found that European-American cultures consist as a pure race and that Black Americans are a new culture. This new culture was one that its community intended not to serve its inhabitants but to serve its owners. Along with this inability to experience freedom, the communities of enslaved people had a myriad of negative social conditions. In order to survive, they developed their own language, rituals, folklore, and religion to support one another. The new behaviors of support have passed on to today's generations. Until society addresses Black Americans’ health issues in relation to their culture, there can be no adequate solutions to issues concerning the Black American and their needs for culturally-appropriate end-of-life care.

Musa, Schultz, Harris, Silverman, and et al. (2009) recognized that trust in an individual physician was totally different than trust in doctors. The individual relationship was not identified in prior research on the problem of distrust. Musa et al. also reported that elderly Blacks spent more time with their physicians than the younger generation of Blacks. Musa et al. reported that Black Americans have a strong mistrust of persons in medicine, government, and science, which may affect their ability to complete ADs.

In a qualitative study with Black American adults (n = 33) -Smith, Thomas, Williams, and Moody-Ayers (1999) identified barriers that prevent Black Americans from completing ADs. -Smith et al. concluded that Black Americans mistrust doctors, scientists, and government. Many participants in five focus groups were concerned about unethical conduct of clinicians when caring for minority patients. Participants mentioned historical mistreatment of Black Americans, specifically the Tuskegee Syphilis Experiment (Jones, 1981). Some participants also viewed signing of documents as surrendering their autonomous rights and giving the doctor legal rights to protect the doctor from punishment. Overall, the participants gave mistrust of the medical community as an outstanding factor for not participating in medical research programs. Waters (2000) reinforced the same sentiments, adding that Black Americans have a real or perceived fear of exploitation when participating in medical research. Because of lack of understanding about ADs, elderly Black Americans may view ADs as a research endeavor.

Experiential Context

I have practiced as a clinical nurse for over 30 years and worked in Neonatal Intensive Care, Labor and Delivery, Emergency Care, and Anesthesia as an advanced practice clinician. More times than I care to remember, I have suffered with families struggling over the “right” thing to do when a loved one is at the end-of-life. As a Black American, I have witnessed people of my culture have trouble with making well-informed, educated decisions about end-of-life care. Moreover, on many occasions, I have heard and seen Black American families and patients express what I believe is a fatalistic view about their concerns by saying, “Leave it in the hands of God.”

Fatalism, in general, is a mental attitude resulting from acceptance of the doctrine that everything that happens is predicted and inevitable. Freeman (1989) suggested that poverty is the prism through which fatalism could be viewed. The characteristics associated with poverty control the role of fatalism. Factors include a lack of education, racism, discrimination, unemployment, lack of access to healthcare and outcomes, and day-to-day survival. Powe and Johnson (1995) concluded that although living with anxiety is not a cause for a fatalistic view, torment and fear along with a pessimistic belief and despair hold significance for African Americans fatalistic view. Powe and Finnie (2003) performed a literature review of fatalism. The authors found that nothing has changed in the underserved African-American community regarding their fatalistic view on healthcare and outcomes.

I have seen the torment and pain when Black American families have tried to "do the right thing," but the family had no idea of what else, or what the right thing was. Therefore, they say, “Do anything and everything you can to keep them alive; we just want them to be comfortable.” These disheartening experiences of mental anguish and their pain have tormented me because I have wanted to guide Black American patients into a different direction. My aims were often different from the decision the Black American families wanted to take. The pain I felt was their pain as I watched them struggle with choices they were not able to make. I could see fear, suffering, and anxiety in my elderly Black American patients’ eyes. The confusion, despair, and hopelessness these families struggled with haunt me today.

I have witnessed that many Black Americans choose not to participate in completing AD documents when given the opportunity to do so. These personal experiences are what motivated me and led me to this study. I believe as a patient advocate guided by the C*ode of Ethics for Nurses* (ANA, 2001), I have a duty to my profession and myself to attempt to be a part of alleviating undue suffering by attempting to improve the quality of death for the elderly Black American population. The researcher's believed the phenomena of elderly Black Americans' perceptions about ADs provided the data necessary to gain a better understanding of this issue.

The researcher was determined to explore the meanings and tools needed to improve end-of-life care for the elderly Black American. The researcher conducted this research because of the need she perceives as a major healthcare issue of elderly Black Americans. One of the major challenges that the researcher identified was the problem the care the elderly Black Americans received at the end of their life. The researcher feels that ADs are a measure to help reduce disparities about quality of life at the end of life in this underserved population.

As a result of the afore-mentioned concerns of the researcher, the researcher had issues that she felt must be addressed to accomplish the goal of quality end-of-life care for the elderly Black American. The researcher's biases arise from over 30 years of clinical experience in the acute care hospital setting. The researcher wanted to gain insight into the reason for lack of use of ADs by the elderly Black American population.

The researcher felt the knowledge gained by this research could add to the body of knowledge to help alleviate needless end-of-life care for this underserved population. The knowledge gained could then be transferrable across the entire Black American population (Morse, 1991). The researcher attempted to used "bracketing" or "epoche." Bracketing, according to Creswell (1998), refers to the act of suspending or laying aside the researcher's accumulation of previous knowledge and bias regarding the experience. Bracketing or epoching involves relinquishing any preconceived notions about the content of the research (Creswell, 1998, 2002, 2005, 2007; Miles & Huberman, 1994; Sandelowski, Barroso, and Volis, 2003; Sandelowski, 2000, 2004; Streubert & Carpenter, 1999; Streubert et al., 2003; van Manen, 1990).

Bracketing was, however, a necessary technique to attempt to ensure credibility and to answer the research question. By bracketing, the researcher was able to gain the knowledge necessary to improve the outcomes of quality end-of-life care for the elderly Black American population. Member checking increased the credibility of this research by evaluating the research findings with research participants.

The researcher employed journaling, audiotaping, and reflection to promote bracketing (Appleton, 1995; Creswell, 1998, 2002, 2005, 2007; Guba & Lincoln, 1981; Miles & Huberman, 1994; Sandelowski perceptions et al., 2003; Sandelowski, 2000, 2004; Streubert & Carpenter, 1999; Streubert et al., 2003; van Manen, 1990). The researcher used peer review in her dissertation with her committee members, experts in qualitative inquiry. The proposed research addressed findings allowed the philosophical ontological and epistemological assumptions of the qualitative, naturalistic paradigm of perceptions of elderly Black Americans about ADs(Creswell, 1998).

Culture

The culture of the Black American and especially the elderly Black American are distinct with unique cultural practices. When attempting to discuss preplanned end-of life care issues with the elderly Black American, cultural differences should be taken onto account. For example, the impact of slavery, discrimination practices that continue despite the advances since the Civil Rights movement of the ‘60s, religion and the priority of spirituality within the Black community, illiteracy, poverty and education or lack thereof are just a few of these differences (Williams, 2006).

African Americans as a group remain at a significantly different depressed economic, educational, and social disadvantage, relative to European Americans (Williams, 2006). There are many minority variations of cultures of Black Americans in the United States. Black Americans may be of different ethnicities and have differing cultural practices while still belonging to the Black race. Black Americans that have migrated from other areas of the world are not of the same heritage of the target population for this study. The Black American participants recruited for this research represented persons from the only culture that been enslaved in the U.S. Persons that belong to the culture with descendants that were slaves produced a different culture than that of other Black Americans in this country.

Decker and Reed (2005) performed research pertaining to elderly persons' preferences for end-of-life care. The participant selection contained elderly persons over 60 years old who were able to function independently or semi-independently within their various community settings. Decker and Reed (2005) used the modified Defining Issues Test(DIT) to measure the level of integrated moral reasoning about end-of-life moral dilemmas. The DIT scale consisted of end-of-life moral dilemmas. On the DIT, there were 14 items to measure moral development to gain understanding the process of end-of-life decisions. Decker and Reed's (2005) findings may explain the reason that some African Americans prefer more aggressive end-of-life treatment. Although their study consisted of a 90% majority White population, their conclusions may aid in a better understanding of the perceptions of the elderly Black American about ADs.

Fischer, Sauaia, and Kutner (2007) discussed that ADs may produce threats to dignity, family relationships, social networks, self-concept/self-ego, spirituality, and trust of the medical system for the elderly Black American. The factors noted may be an asset to assist in the development of nursing intervention dialogue with a focus on development of a culturally appropriate AD for the elderly Black American. For example, a patient-centered approach is required when asking someone to make a decision about ADs. This involves transferring power and authority away from healthcare professionals and toward the patient. A patient-centered approach empowers the patient to be an active participant in decisions affecting ADs for the elderly Black American (Fischer et al., 2007).

Shrank et al. (2005) conducted a qualitative study to explore the content and structure of end-of-life discussions that would optimize decision making. Shrank et al. (2005) recruited a purposeful sample of voluntary participants, at least 50 years old, from two diverse groups of patients that varied in ethnicity and socioeconomic status. Six focus groups in the Denver, Colorado area were conducted. Participants included non-Hispanic White patients recruited from a university hospital and African American patients recruited from a municipal hospital.

Shrank et al. (2005) used a hypothetical scenario vignette of a dying relative to explore preferences for the content and structure of communication. The vignette provided the content for the structured interview that followed with focus group participants. Content analysis was used to obtain results of focus group transcripts. Shrank et al. concluded that practitioners should communicate with patients and patients' families and consider cultural differences and then make note of their goals when making decisions related to end-of life care.

Advance Directives

The concept of advanced end-of-life care planning or an AD is not new. Louis Kutner (1975) first proposed the concept of a living will (LW) nearly 30 years ago. On November 5, 1990, Congress passed the Patient Self-Determination Act (PSDA). The PSDA became effective December 1, 1991 (Patient Self-Determination Act, 1991). The PSDA was enacted as part of the deficit reduction effort of the Omnibus Budget Reconciliation Act (PL 101-508) of 1990. The PSDA is a law to ensure patient rights to dignity, personal autonomy, and comfort in matters pertaining to their healthcare (Doukas & Hardwig, 2003; Thrall & Hudson, 2005).

The PSDA legislation requires Medicare- and/or Medicaid-eligible hospitals to provide patients with AD information at time of admission. Such information about AD documentation is a way to educate people about ADs and promote completion of AD documents. Individuals have the option to complete or refuse to complete AD documents, even though hospitals are required to offer this information. The PSDA prohibits agencies from discriminating against patients who do not have AD documents. The PSDA legislation requires organizations to provide ongoing community education on ADs (Patient Self-Determination Act, 1991).

An AD can contain a LW or a Durable Power of Attorney for Healthcare (DPOA-HC). These documents are different from a standard will. A standard will is an allocation of assets. A LW is an AD that provides instructions for the kind of medical care an individual would or would not want and under what circumstances.

A surrogate decision-maker is a person legally authorized to make decisions on behalf of an incapacitated person. The establishment of authority by the surrogate decision-maker is through the legal document called the DPOA-HC. A DPOA-HC is created through a court proceeding or as authorized by state laws. As assurance, a durable power of attorney may not cancel someone's AD (Hospice and Palliative Nurses Association [HPNA], 2004).

An AD is a legally binding document that indicates the intentions of the patient about any medical care decisions. The AD avoids any unwanted potentially life-sustaining interventions such as resuscitation, artificial nutrition and hydration, dialysis, and antibiotic therapy. AD documents can authorize withdraw any interventions that have already begun. Although hospitals are mandated by Medicaid and Medicare guidelines to introduce AD documentation to patients upon admission, the PSDA legislation also specifies it is up to the patient's discretion to complete the AD (Patient Self-Determination Act, 1991).

Diversity and Advance Directives

The need and significance of culturally appropriate education was demonstrated in the Hawthorne et al. (2006) meta-analysis. Hawthorne et al. performed electronic searches of databases using ethnic minority groups with high incidence of illnesses such as diabetes and high blood pressure. Quality of life measures were often used in multiple studies as a correlate for incidence of specific illnesses. The search strategy identified 125 citations, with 117 that were potentially relevant to the topic of culture and health education.

In three studies reviewed, knowledge scores related to culture and health education improved in the intervention groups at six months. In the meta-analysis, there was one long-term follow-up study and one formal cost-effectiveness evaluation. Hawthorne et al. concluded that culturally appropriate health education would be more effective than the health educational methods used in the past. The meta-analysis identified learning points to direct future research and the need for culturally appropriate education for all minority groups.

Although the meta-analysis by Hawthorne et al. (2006) examined the difference of educational methods for minority groups, their recommendations have potential across all ethnic and minority cultures. Hawthorne et al. use of a meta-analysis is important to the current study as health professionals who present the concept of ADs to others may or may not be from that person's culture. Hawthorne et al. concluded that the concept of "otherness" is an important concept in communicating and educating diverse minority groups. They also discussed philosophical issues related to cultural humility as a quality of seeing the greatness in others and coming into the realization of the dignity and worth of others, even when they are different from ourselves.

Diversity includes the notion that there are important differences in Black Americans and other "Black" cultures within the Black American community. Cultural diversity, also referred to as multiculturalism, is the variety of human cultures in a region adapting to widely differing conditions (Ayton-Shenker, 2005). The presence of such diversity may be one reason African Americans sign ADs at a lower rate (Bullock, Christ, & Blacker, 2006) than other populations. Specific differences within the "Black" community may account for different approaches and beliefs about end-of-life care and

ADs. However, the reasons for discrepancies in research among minorities may not be apparent due to cumulative research data with different subgroups among cultures not clearly identified in data.

Diversity of different cultures within the Black community may influence the values, beliefs, and meaning of health and illness. If a reduction in health disparities related to signing ADs is to be accomplished as proposed in the goals *Healthy People 2010* initiatives (U.S. Department of Health and Human Services, 2002), a better understanding of the meaning of ADs for elderly Black Americans may be needed. Thomas, Wilson, Christopher, Birch, and Sheps (2009) conducted a literature review that focused on preferences for end-of-life care by individuals with different cultural affiliations and ethnicities. Thomas et al. reviewed 26 studies and reported the results using a narrative systematic review.

Thomas et al. (2009) concluded that Western societies are becoming more sensitive to diversity among cultural groups. The different pre-planned decision making about end-of-life care is predominantly a North American concept. Thomas et al. (2009) concluded their study with four major themes from the literature: advance directives, life support, communication, and decision-making. They determined that substantial differences exist among cultural groups. African Americans prefer life support to Asian Americans or European Americans. Most importantly, the researchers determined that appropriate and adequate communication is essential for end-of life care and healthcare education to improve competent diversity of care.

Education/Knowledge

Freire (2005) claimed that if people are to have real choices, they must be given critical and reflective education. Waters (2000) completed exploratory research that concludes Black Americans are less likely to know about ADs even if they complete them. Waters based her study on the findings of a Portland, Oregon Health Sciences University forum. Waters (2000) conducted a focus group discussion with interventional materials related to ADs. During the group discussion, she presented a 13-item structured, self-report, investigator-developed Advance Directive Knowledge Attitude Utilization Questionnaire (AD-KAUQ), which was administered to the 27 Black Americans from a community-centered environment. Descriptive statistics were computed on the pre- and post-questionnaire AD-KAUQ, before and after the interventional material related to ADs.

Waters invited participants through a community liaison. She conducted an educational forum in which the participants self-identified themselves as Black American, 21 years of age or older, with a comprehensive understanding of the English language. Waters modified some of the AD-KAUQ items and assured content validity and reliability by the test retest method. She used descriptive statistics to evaluate the results. Although some of the participants (90%) had completed ADs only about one-third (30%) comprehended the meaning.

Waters concluded that more education regarding ADs would be needed among her sample of participants who were middle-aged, middle-class educated Black Americans. She contended that the terms use in end-of-life care choices exceeded the overall comprehension of educated Black Americans. After her educational forum, a significant number of participants concluded they would consider writing an AD. However, the participants still did not actually initiate an AD.

Similar to the intended research, Waters' objective was to verify the lack of knowledge that Black Americans possessed about ADs even after interventional education. The study intended to explore perceptions of elderly Black Americans about ADs. The sentiments in the Waters study compound the fact that more individualized education is needed when attempting to initiate ADs. However, during the research phase, the participant would have an opportunity to be informed about ADs and have an opportunity to clarify any misconceptions that may exist.

The studies by Kiely et al (2001) and Rosenfeld, Wenger, and Kagawa-Singer (2000) suggest the patient's lack of knowledge created a need to make necessary, informed decisions about ADs. Fagerlin and Schneider (2004) emphasized the difficulty individuals may have when they are not equipped with essential knowledge to make decisions about dying. One of the problems identified was that patients and their families were attempting to make decisions about preferences for an unpredictable future when confronted with unidentified illnesses and unpredictable treatments.

Racial Bias

Interference from outside of the Black American community intensifies distrust. This is an important factor to consider when attempting to gain access to information about the perceptions of elderly Black Americans and the need for more explicit cultural understanding of this underserved population. Schiele (2005) identified the high-risk status of Black Americans as the entity that leads to misunderstanding and cultural estrangement. Schiele (2005) conducted a qualitative research study on culture and the high-risk status of Black American couples. His study examined how the culture of the couples produced four risk factors for the Black American. The risk factors are: culture, estrangement, a weakened black collectivism, and spiritual alienation. Sheile concluded that these risk factors have led to repression, cultural subjugation, and social problems.

The information Schiele obtained was derived from a collective focus of income inequality scale specifically the Gini ratio. The Gini ratio is a measurement inequality of African Americans. The Gini ratio ranges from zero, which is perfect equality to one, which is perfect inequality. The scale was acquired from the U.S. Census Bureau (2002). Schiele concluded that cultural estrangement is one cause of risk factors as above in the Black American culture today. The significance of Schiele's conclusion is that Black Americans tend to be isolated and isolate themselves within their Black communities. The elderly Black American is particularly vulnerable to the oppression and racial biases that are common in the U.S. Elderly Black Americans are particularly vulnerable to oppression due their history. Dominance over Black Americans has led to increased mistrust of the medical community. The study below is an example that describes the racial bias in the Black community.

Given the magnitude and persistence of these different views held by Blacks and Whites, it is not surprising that current race relations in the U.S. are full of racial distrust. While the study by Muse et al. was conducted with Caucasians, the design addressed African Americans but not specifically elderly Black Americans. Nor did the researchers allude if their target black population was the same as described by the research.

Anderson (1996) conducted a public opinion poll of 1,200 Black American adults for *The New Yorker* The poll found that the majority of Blacks in America today have a profound distrust for the police and the legal system. About one-third of Blacks are overtly distrustful of Whites in general (Anderson, 1996). This realization could answer the question about distrust of Black Americans and of the healthcare providers, who are still predominantly White. Research conducted in the following studies concluded that in minority communities, specifically Black American communities, experiences within the community environment often minority neighborhoods)and health disparities are frequently related. Additional studies also indicate there is racial bias against African Americans within the medical community (Ashton et al., 2003; Beck, Brown, Boles, & Barnett, 2002; Waters, 2000).

Trust/Distrust

Belcher, Fried, Agostini, and Tin etti (2006) explored the views of medication-related decision making of older adults using a qualitative research design. The researchers believed that patient input would be important in the face of uncertainty and variability about medications. The indication for their study was that little is known about older patients' views of their involvement in medication decision making.

Fifty-one persons at least 65 years old who consumed at least one medication were recruited from three senior centers and four physicians' offices. One-on-one interviews were conducted to uncover participants' perceptions of medication-related decision making through semi-structured, open-ended questions. The transcripts were analyzed with multiple methods suggested by qualitative experts, e. g. Crabtree and Miller (1999) Glaser and Strauss (1967); Strauss and Corbin (1998); Glaser and Strauss, 1967; Strauss and Corbin, 1998; and Crabtree and Miller, 1999. Themes were compared within and across interviews according to the constant comparative method of analysis.

The major premise that emerged was the variability in perceptions concerning whether it was possible or desirable for patients to participate in medication and prescribing decisions. Involvement was limited to the amount of information shared. Physician and system factors that facilitated or hindered patient participation included: communication skills, the expanding number of medications available, multiple physicians prescribing for the same patient, and a focus on treating large numbers of patients. Perceived lack of knowledge, low self-efficacy, and fear were the major patient factors mentioned. Both the presence and absence of trust in the prescribing physician were seen as alternatively impeding and enhancing patient participation. Only one physician explicitly mentioned patient preference as a cornerstone of shared decision-making.

Belcher et al. (2006) concluded that while progression to greater patient involvement in medication decision making may be possible, suggesting this change would be a challenging transition although desirable to some older patients. In reviewing the literature, trust continues to be a major concern of elderly Americans. Although the Belcher et al. above study was based on the involvement of medication and the decision making of older adults, the conclusions of the researchers stretch far beyond medication decision making to the perceptions of elderly Black Americans about ADs.

A quantitative study by Kelly and Floyd (2001) examined the associations of racial perceptions that represent pro- and anti-Black American attitudes or a mixture of these beliefs associated with trust and adjustment for Black American couples. The study centered on the negative stereotyping of aggressive Black women and passive Black men and the negative stereotyping effect on trust in a relationship. The effects of pro-Black American attitudes suggested the need to evaluate a wider range of studies on stereotyping in future research.

An explanation of some of the distrust among patients regarding ADs and the healthcare worker was explained by a study conducted by Coffman (2004). In this qualitative study he examined the cross-cultural experiences of healthcare workers and their patients. Coffman used the meta-ethnographic comparative synthesis method derived from 13 qualitative studies and reported that there remains a limited understanding of the meanings of cultural caring in nursing practice. Although there were originally 18 studies that included a variety of healthcare providers13of the qualitative studies were reduced to six overall themes that describe over 1,000 nurses' experiences caring for patients from other cultures. The themes that emerged included: connecting with the patient cultural discovery, the patients in the context of their world, and roadblocks.

Coffman (2004) concluded that some healthcare workers felt that they lacked the knowledge to care for patients of different cultures. Some of the nurses had little interest in having formal cross-culture training, while the younger nurses felt they might be interested in learning more about different cultures by living in the patients' countries. Coffman's study is another example of the need for cultural education of nurses caring for diverse populations, especially the elderly Black American population.

Coffman concluded that based on historical analysis and clinical experience with Black clients, racism has caused some Blacks to feel inferior to other races. Sometimes one presumes that feelings of inferiority affect trust and promote internalized negative stereotypes and racial profiling.

Blackford (2003) discussed that the participants could misinterpret the consent process usually completed during research. He suggested that understanding the importance of interpersonal trust within the clinical relationship might be a significant factor in enhancing participation in clinical trials. This information could dramatically affect the ability to recruit and retain participants. He also revealed that some Black Americans felt that they were being excluded from certain health services due to their race (Blackford, 2003).

Baldwin, Brown, and Rackley (1990) have theorized that Black Americans have either an Afrocentric worldview in which they have high levels of Black self-consciousness or a Eurocentric worldview in which they operate according to White values and norms, such as attitudes that emphasize individualism, exclusiveness, materialism, and control over nature. Their conclusions could possibly account for some measures of distrust among the 30 elderly Black American populations they studied. Black Americans generally distrust the medical system (Degenholtz, Arnold, Meisel, & Lave, 2002; Perkins, Geppert, Gonzales, Cortez, & Hazuda, 2002).

As a result of studies that discuss distrust a study called the "Tuskegee Legacy Project Questionnaire" was conducted to examine the influence and awareness of the Tuskegee Syphilis Study. President Bill Clinton issued a formal apology for the Tuskegee Syphilis Study (Katz et al., 2006). The Tuskegee Legacy Project Questionnaire was administered to 1,133 adults in four U.S. cities. The 60-item questionnaire addressed issues related to the recruitment of minorities into biomedical studies.

The Tuskegee Legacy Project conclusion showed 50% of Blacks and 70.3% of Caucasians reported that they were less likely to participate because of what they had heard about the Tuskegee Syphilis Study. Katz et al.'s (2006) contribution to research supported what other researchers have found about the hesitancy of Blacks, non-Hispanic Whites, and Hispanics to participate in biomedical research. Researchers and clinicians working in the Black communities in the future must acknowledge the distrust related to the Tuskegee Study. Katz et al.'s research emphasized the importance for healthcare workers to create a respectful, comfortable, and inviting atmosphere for people who are introduced to AD information. Katz et al.'s findings provided concerns about recruitment of elderly Black Americans for the intended research.

Jacob et al. (2006) wanted to further understand what trust and mistrust in physicians means to Black Americans. They used nine focus groups with a convenience sample of participants recruited from a public hospital clinic and a community advocacy organization in Chicago. Their study concluded that perceptions of physicians' greed, racism, and expectations of experimentation in routine medical care contributed to the Black Americans' distrust of physicians, which reinforces the distrust of Black Americans of the medical community. Distrust negatively relates directly to the acceptance of and willingness to ask questions about ADs(-Smith et al., 1999). Unique factors contribute to trust and distrust in physicians and the medical community as a whole in Black American patients (Degenholtz et al., 2002).

Family/Social Support

Other factors that have been fund to impact the Black Americans' resistance to completing ADs are social and family support. Family relationships were mentioned in every interview question asked by the researchers. Subjects expressed great confidence in families to make end-of-life decisions for them (Langford, Bowsher, Maloney, & Lillis, 1997). The participants did not want to be a burden to their families. The interesting point about the study was that the participants made their wishes known to their families but would not document them in the form of an AD (Dupree, 2000).

Dupree conducted a qualitative research study to describe how some Black Americans view ADs. The literature reviewed for her study revealed that most prior studies used quantitative methods with force-choice questions. Prior studies also had few Black subjects. Dupree selected 17 Black Americans, drawn from a purposive sample of Black Americans aged greater than 18 years and self-identified as a Black American.

The participants used in Dupree's study also must have made contact with the healthcare system subsequent to the passage of the PSDA in 1991. In addition, they must not have completed an AD or, after being exposed to information about ADs, chose not to complete one. The interview was used with a semi-structured guide for the method of data collection. The data was then subjected to content analysis following steps described by Kvale (1996), Miles and Huberman (1994), and Lincoln and Guba (1985).

The ideas expressed by the subjects were in response to questions about ADs. Dupree (2000) found that participants' descriptions of ADs converged into three major categories: threats to dignity, family relationships, and spirituality.

Social support is a valuable theory in nursing because of its impact on health-related issues. Social support has many positive consequences (Langford et al., 1997). Coping is a positive consequence of social support. Coping, as a resource and a buffering agent, decreases anxiety (Baldwin et al., 1990). Coping protects individuals against the negative effects and deleterious impact of stressful situations, thereby changing the experience itself. Questions and confusion remain as to how to best define social support and how it operates (Antonucci & Sherman, 1997). Social support, as a general concept, also refers to the value an individual accrues from her/his network of social ties, which can include family, friends, and/or significant others (Tracey, 1990). Due to the greater ease in connecting with someone who has familiar preferences, styles, language, and daily life experiences, bonding relationships are one of the foundations of coping in the social world (Lincoln, 2000).

The literature review assessed the significance of family and close friends in the role of social support networks and the dramatic effect support networks can exert on an individual in the decision making process about end-of life care. The essence of this literature review found that the thoughts about and decisions related to ADs can produce threats to dignity, family relationships, social networks, self-concept/self-ego, and autonomy to this underserved population (Riley, Brennan, & Powell, 2004). The ideas expressed in the study by Dupree (2000) concluded that if participants signed an AD, such an act might have produced threats to family and close friends. Other studies agree with this conclusion in that elderly Black Americans with strong religious beliefs often wanted their family or their doctor to decide their end-of-life needs, if they were incapacitated to do so (Beck et al., 2002; Coffman, 2004; Waters, 2000). In the many studies conducted, no one knows if the patients discussed their decisions with their families prior to making those decisions.

Conflict

Porter-O’Grady (2004), Bradley (2005), Dupree (2000), and Waters (2000) all implied that discussing ADs might initiate conflict within the family or support networks. Conflict is an integral part of the fabric of our postmodern society, which is litigious, competitive, complex, and alienating. Human dynamics include the potential for conflict. Communication processes have deeply embedded in them all the elements of essential conflict. Conflict can be associated with discomfort, pain, and threats to social support networks (Strack and Deutsch, 2004).

Race, age, a patient's attitude, and mistrust of the healthcare system can cause use conflict with regard to ADs. In 1999, a study was performed to determine if there was a difference in the attitude between Black and White physicians regarding end-of- life planning. The study concluded that the attitude about end-of-life care matched according to ethnicity. Therefore, the impact of conflict might be muted in light of other stressors associated with social and economic disadvantages if the patients had doctors with the same ethnic background. The study concluded that low socioeconomic status or lack of familiarity with treatments account for the difference in attitude about ADs (Melbane, Oman, Kroonen, & Goldstein, 1999).

Elderly Black Americans have different views about death and dying than younger Black Americans. The difference of views about dying between older and younger Black Americans has been a cause of family conflict Older people do not want anyone around when they die while adult children were full of remorse and guilt if they were not around at the end of their love ones death (Cicirelli, 2002). Because use of the mistrust of the healthcare system by elderly Black Americans. Rawlings-Anderson's (2004) research concluded it is vital that health-care professionals ascertain how individuals are viewed within their culture because use this will have an influence on the social support they receive.

Spirituality/Religious Beliefs

The solitary item could not be taken away from the Black Americans and what Rawlings-Anderson's (2004) research concluded solidarity as vital that healthcare professionals ascertain how individuals are viewed within their culture because this has an influence on the social support they receive.

Religion was an item that could not be taken away from Black Americans. Religion was used to console their inner tranquility and provide a sense of serenity, harmony, and peace. Research supports the fact that spirituality and religious beliefs affect the attitude of Black Americans about ADs (Rawlings-Anderson, 2004). Erikson and Erikson's theory (1997) on spirituality suggests that spirituality permeates all human experiences rather than being additional to them.

Spirituality is deeply embedded in the health life-span development of people from the Black Diasporas (Wheeler et al., 2002). Black Americans place a great significance on religion. Spirituality is the use of one's faith in a higher being or in the universal order of things to make sense of the trauma or increase one's feelings of efficacy in handling the effects of the trauma. Spirituality, historically, has been noted as prominent in Black American culture.

Spirituality has been recognized as a coping strategy for people in general and Black Americans in particular (Joseph, 1998). Individuals use spirituality as a strategy. Prayer is considered a religious ritual and is attached to religious beliefs (Pargament & Mahoney, 2002).Wheeler et al. (2002) discussed the problems of Western theories using

Erikson’s model of life-span development as an example. The researchers presented the definition of spirituality using a Black-centered lens and then proposed a synthesis between Western and non-Western developmental theories with the issue of spirituality placed in the center of analysis. They concluded that it is spirituality within the psychological stages of development that the Western theorists have failed to confront when advocating the use ADs by Black Americans. However, in their exploratory study, religiosity and end-of-life care planning were viewed as a paradox or contradiction.

Some recent work on meaning and spirituality is focused on how seemingly non-secular aspects of life can be perceived as having spiritual character and significance (Holt & McClure, 2006). For example, an elderly Black American might view the act of instituting an AD as a spiritual event, although most Western health professionals view the action as purely a medical procedure (Waters, 2000). An elderly Black American may also believe that God is the determinant of death. The act of dying is closely associated with religion and God within the elderly Black American population.

In the article review of the literature by Johnson, Elbert-Avila, and Tulsky (2005), the authors wanted to review the literature of spiritual beliefs that may influence the treatment decisions of African Americans. Populations included community-dwelling older people, nursing home residents, hospitalized patients, and those with human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), cancer, diabetes mellitus, and end-stage renal disease. The studies that offered primarily commentary, reviewed existing literature, addressed health promotion and disease screening, or explored the importance of spirituality without emphasis on illness were excluded.

Using questions adapted from critical appraisal guides (Glacomini, Cook, & Guyatt, 2002; Crombie, 1996), the authors independently evaluated the quality of all papers meeting inclusion criteria. Studies were reviewed for appropriateness of the sample, methods, measures, and analysis. Glacomini et al. discussed conflicting responses to the evaluation of the questions. Twenty-seven papers addressed spiritual beliefs influencing treatment decisions throughout the course of illness, and 13 addressed spiritual beliefs specific to decisions at the end of life.

A dominant theme emerged stressing the importance of spiritual beliefs and practices. Overlapping themes included the belief that only God has the power to decide life and death and a belief in divine intervention or miracles. This review suggests that their spiritual beliefs strongly guide many African Americans as they cope with illness and the end of life. The results also found that spiritual beliefs in the face of adversity are embraced as a survival guide put in place by a higher power.

In addition to serving as a source of comfort, coping, and support, for some African Americans, spiritual beliefs and practices provide a foundation for understanding disease, restoring health, and making treatment decisions. The authors concluded that an increased understanding of and respect for cultural differences in spiritual beliefs and the effect of these beliefs on treatment preferences lead to improved communication and reduce conflict in the care of patients of all ethnic groups.

Cultural beliefs are passed down through generations, influence accepted norms and taboos within a community, and are often linked to adherence to a particular religion. There is a relational increase in spirituality among older adults (Holland & Neimeyer, 2005). The role that spirituality may play in coping with change and loss increases with advancing age. It is possible that changes in spirituality often attributed to age are more accurately attributable to the experience of coping with the changes in health status and social role that typically occur with aging. Perhaps age differences did not emerge in the sample because all participants were coping with significant change and loss associated with the onset or exacerbation of a life-disrupting illness or injury (Schneiders, 1997).

In a qualitative study by Holt and McClure (2006), the authors examined the perceptions of the religiosity-health connection among Black American church members (n = 33; ages 34-84) who were members in six churches. They use the key search words “religion,” “spirituality,” and “Black American.” They conducted 33 interviews with church members, from 6 churches, ages 34 to 84 years of age. Researchers used an open-coding scheme from the data using an inductive process.

From the study by Holt and McClure, themes emerged including spiritual health, one’s mental health effect on physical health, importance of the church family giving problems up to God, and the body as a temple of God. The idea that was most significant to the intended research was the emergent theme of spiritual health. The participants from the study expressed the notion of having a healthy spirit or spiritual health. The idea of having a healthy spirit was viewed as more important than being physically healthy since spiritual health connected to physical health. The authors implied that future researchers might need to explore the connection between religiosity and health as a way to understand the mechanisms that guide elderly Black Americans perceptions about ADs.

Crystal Moore (1999) presented a study of 20 participants; 9 of the participants were minorities. Semi-structured interviews together with qualitative methodology were used to determine the factors that influence elderly Black Americans perceptions about Ads. Negative case analysis was used to account for the variability of all interview responses. The researcher presented categories in the reasoned action theory framework that included religious beliefs that figured prominently in medical treatment planning for minority seniors.

In a qualitative study, Shellman (2004) wanted to explore research to increase the knowledge available about] the cultural heritage, worldviews, and life experiences of elderly Black Americans (n = 7). Reminiscence interviews were conducted with seven elderly Black Americans, from church communities, living in a medium-sized northeast urban community. Data were analyzed using Spiegelberg’s phenomenological method. All of the participants were born in the United States and reared in the southern part of the United States. Four of the participants were women, and three were men.

Shellman concluded by discussing how decision making and spirituality were related to end-of-life care. Although spirituality was indicated as a major factor in decision making and the association with advancing age, Shellman noted that additional studies are needed to explore the healthcare decision making process related to ADs. Few studies expounded on this premise. The above-mentioned studies supported the importance of religiosity/spirituality to elderly Black Americans (Armstrong & Crowther, 2002).

Pain/Discomfort

The concept of pain and discomfort are related but poorly conceptualized (Ridner, 2004). The term “distress” is commonly used by patients to describe discomfort related to conditions that might be associated with conditions other than physical pain, such as mental or emotional discomfort (Gulanick, 2003)

The concept of discomfort may be linked to ADs and elderly Black Americans. While racial or cultural barriers related to pain and discomfort have not been described, these concepts may have additional qualifying features to the elderly Black American culture and their perceptions about ADs. Psychological distress is the unique discomforting emotional state experienced by an individual in response to a specific stressor or demand that can result in perceived harm, whether either temporary or permanent. Pain serves as a protective mechanism (Ridner, 2004).

Pain usually cause uses a person to seek counsel. Pain is the symptom that most frequently cause an individual to seek assistance for health problems. McGraph (2002) describes spiritual pain and discomfort in very similar ways. Spiritual discomfort is conceptualized as an experience of profound disharmony in the person’s belief or value system that threatens the meanings of life. During spiritual distress, an individual may become separated from his or her personal source of comfort and strength. Spiritual pain is a state of conflict between one’s own belief system and current reality; it is an experience of conflict and disharmony between a person’s hopes, values, beliefs, and his or her existential experience with life.

In the evaluation of the literature, the research by Bradley (2005) and Tilden, Tolle, Drarch, and Perrin (2004), included pain and the association of an uncomfortable death. The authors specifically discussed aspects of patients wanting to avoid pain and seek comfort at the end of life, including during the process of dying. McGraph (2002) described spiritual pain and discomfort in very similar ways. Spiritual discomfort is conceptualized as an experience of profound disharmony in the person’s belief or value system that threatens the meanings of life. During spiritual distress, an individual may be separated from his or her personal source of comfort and strength. Spiritual pain is a state of conflict between one's own belief system and current reality.

Avoidance

Avoidance was a concept uncovered during the literature review. By using avoidance, the elderly Black American can alleviate the unpleasantness of facing end-of-life care planning that could include ADs. Some research has indicated that avoidance arises out of an individual's anticipation that the engagement was a challenge to self-concept and anxiety-producing situations (Riley, Brennan, & Powell, 2004). Awareness of avoidance strategies used by elderly Black Americans may or may not intentionally be the one prerequisite that proved to be of value in overcoming avoidance.

Chapter Summary

Research and the historical context about the development of ADs coupled with threats to social and family networks, conflict, trust, pain, lack of education, the influence of religion, lack of education, and avoidance are all negative characteristics that in combination may influence the perceptions of elderly Black Americans away from expressing their perceptions about ADs. The literature reviewed was focused on research that included mention of either ADs or elderly Black Americans and the impact of major decision making in preplanned end-of-life care.

CHAPTER THREE

Methods

Introduction/Overview

The purpose of this research was to explore the perceptions of elderly Black Americans about ADs. The Black minority in a society that is dominated by the White majority presents a different ethnic group, with intangible individual differences that are unlike those of any other minority ethnic group (Smelser & Syme, 2000). Data collected by Woolf, Satcher, Johnson, Fryer, and Rust (2004) during the years 1991 through 2000 found that African American death rates were in excess of five times that of Whites. Woolf et al. also found that improved health outcomes and decreased health disparities among African Americans could be achieved by correcting the imbalances in social inequalities that influence health within African-American ethnic groups.

Research Design

An exploratory descriptive research design was used to broaden the knowledge about elderly Black Americans' perceptions about Ads and end-of-life care. The study to explore elderly Black Americans' perceptions about ADs was one way to help decrease healthcare disparities in an attempt to broaden evidence-based improvements in elderly Black Americans' end-of-life care (Woolf, et al., 2004; U. S. Department of Health and Human Services, 2000). In qualitative traditions, information gained during interviews is considered to be data (Rubin &Rubin, 2005). To explore the "perceptions" the researcher approached the subject from a post-positivist paradigm, structured specifically and systematically using a qualitative exploratory descriptive method as outlined by Miles and Huberman (1994).

The researcher analyzed the data using an interpretive descriptive approach. Qualitative research methodology integrates components from the social sciences (Lincoln & Guba, 1985; Miles& Huberman, 1994; Sandelowski, 2000; Thorne, Oglov, Armstrong, & Hislop, 2007; Thorne, Kirkham, & MacDonald-Emes, 1997).The goal of this research study was to add to the body of nursing knowledge. The goal of qualitative research is not to generalize but to gain an in-depth understanding and knowledge of particular phenomena (Morse, 1994). In the qualitative research paradigm qualitative research brings about greater sensitivity to the phenomena being investigated (Thorne et al., 1997).

About the Interview Questions

The interview questions were devised to explore the research question: What is the perception of elderly Black Americans perceptions about ADs? The interviews followed a script (see Appendix K labeled “Interview Guide”) used by the researcher who was the only investigator used in this research to collect data. The generation of questions was elicited by participant responses to the research questions. The researcher kept field notes in a journal to augment information obtained from the interview. Field notes helped to frame the researcher’s biases. Saturation occurred as the researcher felt no new information was going to be obtained (Creswell, 2002/2005). The anticipated number of participants was estimated to be 20 and was suggested as the maximum number of participants needed to conduct this type of qualitative research (Creswell, 2002).

Qualitative Research

Qualitative researchers use “real-world” settings with a naturalistic approach to comprehend and to extrapolate knowledge from a situation. Qualitative researchers embrace their research while attempting not to impose (bracket and or epoch) themselves within the research process (Miles & Huberman, 1994; Speziale & Carpenter, 2003; Struebert & Carpenter, 1999). The qualitative research approach was used in an attempt to broaden evidence-based improvements in elderly Black Americans’ end-of-life care and in an attempt to decrease health disparities within this population’s racial community (Woolf, 2004; U.S. Department of Health and Human Services, 2000).

A major difference in the assumptions posed by quantitative and qualitative researchers is that qualitative research disputes that there is only one reality, or one way of knowing, or one universal truth. As in quantitative research, the researchers must test the value and integrity of their research. Research rigor serves as the check or testing process. (Sandelowski, 2000). Leininger (1991) argued that qualitative research findings should be tested for accuracy using terms and criteria that have been developed exclusively for the qualitative approach, rather than the quantitative approach. Some researchers have discussed the preconceived lack of usefulness of qualitative designs. However, Sandelowski, et al. (2003) are respected qualitative researchers and methodologists who have suggested that to strengthen the credibility of qualitative investigations; qualitative researchers should increase efforts to integrate and to synthesize qualitative findings.

The exploration of elderly Black Americans’ perceptions about ADs supports a postmodern perspective and a qualitative methodology over a quantitative positivist design. Lincoln and Guba (1985) asserted that qualitative research is a replacement for a conventional, scientific, or positivist paradigm of inquiry. The Constructivist philosophy is ideal because what is “real’ is a construction in the minds of individuals. A qualitative Constructivist philosophical foundation is appropriate to guide the researcher to explore the perceptions of elderly Black Americans about ADs. The philosophical stance is consistent with seeking to understand through descriptive exploratory inquiry methods (Giorgi, 1997).

Anthropologists conducting ethnographies in remote cultures first used qualitative approaches in health-related research (Rivers, 1924). Exploratory research that was used for the current study most commonly occurs in field settings, with investigators collecting data through participant observation and interviews and analyzing data through thematic content analysis (Colaizzi, 1978). This study is being conducted in the field, with the researcher and the participants choosing the place for the one-on-one, face-to-face interviews.

Qualitative research as a method of health research in nursing is rising in popularity. Qualitative research includes a variety of assorted approach to generate knowledge through the eyes of the researcher. Sandelowski’s approach (2004) to qualitative inquiry as an exploration was useful when the researcher believed that a more specific approach such as grounded theory or phenomenology was premature (Sandelowski). Sandelowski’s suggested methodology allowed the researcher to explore and construct a picture of perceptions about ADs and preplanned end-of-life care that may be both difficult and emotionally agonizing for the elderly Black American population.

Miles and Huberman's (1994) approach was also used for the exploration and descriptions of the participants' perceptions about ADs. The researcher hoped to gain knowledge that repressed true interpretations of the participants as seen through the researcher's eyes. Bevis and Murray (1990) and Hagle, Kirchhoff, Knafl, and Bevis (1986) forecasted that the postmodern transition and evolution of qualitative research would be a natural maturational philosophy of nursing. These beliefs continue to hold true for many researchers today.

In this study, the researcher was the instrument through which the phenomenon was explored. The value of the exploration of the perceptions of elderly Black Americans was in the value of additional knowledge gained through the voices of the participants as they spoke with the researcher about their perceptions of ADs (Beidler, 2002). A premise about qualitative-research when exploring the perceptions of elderly Black Americans regarding ADs is that nursing consists of interactions between unique individuals with unique experiences.

Interactions between the researcher and the participants taking place within unique situations are well suited for understanding but not predicting (Sarvimaki, 1988). The subjective experience obtained by collecting data was missing from traditional quantitative-research methodologies (Omery, 1983) and is now made possible by the utilization of a qualitative paradigm with a different base of assumptions and methods about the nature of reality (Creswell, 2005).

By using the qualitative approach the researcher was able to describe the reality as experienced through the lens of the elderly Black American and to define elderly Black Americans' perceptions through their realties, truths. The study utilized the descriptive exploratory qualitative design (Miles & Huberman, 1994Diverging from traditional qualitative methodologies approaches was necessary to explore the perceptions of elderly Black Americans. The exploratory descriptive methodology was used due to the need for the researcher, a nurse, to move beyond traditional restraints imposed by quantitative methodologies. The information gained by using the exploratory research method led to the development of credible and meaningful disciplinary knowledge (Sandelowski, 1986; Sandelowski et al., 2003; Sandelowski, 2000; Thorne et al., 1997). The researcher did not discover any previous literature that explicitly described the perceptions of elderly Black Americans about ADs.

Elderly Black Americans have specific needs and identities that require addressing for implementing culturally appropriate end-of-life care. Exploring elderly Black Americans' perceptions about ADs may allow nurses to empower themselves in order to deliver improved end-of-life care for this underserved population. The goal is to understand, explain, and make a particular phenomenon clear through thick, in-depth descriptions of elderly Black Americans' perceptions about ADs (Estabrooks, Field & Morse, 1994).

Qualitative research involves the interpretation or the explanation of phenomena as described through the researcher's lens. Each phenomenon of interest is explored through researcher-participant interaction. Data is interpreted through the researcher's understanding of the reality of the participants. The researcher becomes the instrument through which the participant speaks. The researcher attempts to interpret the participants' meaning as seen through the participants' lens. The implications of the interpretation require interaction between the researcher and the participants, in this case to develop a common understanding of elderly Black Americans' perceptions about ADs.

As data are collected, the researcher becomes immersed within the phenomena. Depending on the beliefs of the researcher, the researcher may attempt to set aside (bracket) preconceived notions, that is, any previous knowledge, beliefs, or premonitions about the phenomena under investigation (Creswell, 2003). Neutrality refers to freedom from bias in the research process (Sandelowski, 1986). Neutrality is a concept that is difficult to achieve. The researcher addressed ethical considerations about her own ability and set aside her emotions (epoching) to remain objective throughout the entire research process (Appleton, 1995).

Concerns exist about the ability of qualitative research to resolve "real-world" problems. Methodology for the qualitative research paradigm continues to be debated. The establishment of qualitative approaches is respected and accepted, particularly in the social sciences such as education, psychology, and nursing is a valid credible form of research (Creswell, 2007). Some researchers have discussed the preconceived lack of usefulness of qualitative designs. However, Sandelowski et al (2003), who are respected qualitative researchers and methodologists, have suggested that to strengthen the credibility of qualitative investigations, qualitative researchers should increase efforts to integrate and to synthesize qualitative findings.

The qualitative research method was used to explore the meaning of the social phenomena, perceptions of elderly Black Americans about ADs, through the individuals' lens by exploring elderly Black Americans' perceptions about ADs. The intent was that knowledge interpreted with qualitative research methods might increase knowledge of elderly Black Americans' perceptions about ADs and end-of-life care (van Manen, 1990).

Results from this study may foster changes in nursing practice as nurses' address issues related to ADs, end-of-life care, and the elderly Black American. The exploration of elderly Black Americans' perceptions about ADs has not been addressed in the South Florida Black American population. Since there is a paucity of knowledge about elderly Black Americans' perceptions about ADs, an exploratory qualitative research design was an appropriate research method to use (Creswell, 2007; Miles & Huberman, 1994).

Sample and Setting

The elderly Black American participants were chosen based on the research question, the population of interest, and the access to the individuals to be studied. A volunteer self-referred population of 20 elderly Black American adults, who may attend one of the community centers or churches(see Appendix G, Labeled "Recruitment Facilities"), was recruited. Potential participants obtained information via a recruitment flyer (see Appendix I, Labeled "Recruitment Flyer") posted on bulletin boards at the facility or published in newsletters and/or church bulletins. Word-of-mouth and snowball sampling were also used.

Interested persons were contacted by the researcher for further explanation and possible enrollment in the study. If the participant agreed and self-identified as a Black American 65 years or older, a time and place, mutually agreed upon by both parties, was set for the first interview. The researcher collected part of the information used for the demographic questionnaire. At the beginning of the initial audiotaped interview, the researcher and the participant completed a demographic questionnaire data sheet, and the participant was given a referral form (see Appendix L, Labeled “Support Information for Participant”) at the beginning of the one to one interviews and consent was obtained.

The consent was obtained according to approved IRB procedures, and a copy was given to the participant. The researcher had equipment with her capable of making photocopies. The participant or researcher could have stopped the interview at any time, and for any reason. The participant also could refuse to answer any questions or request that the audiotaping be stopped. If the participant refused to have the interview audiotaped, were not enrolled in the study (Creswell, 1998, 2002, 2005, 2007; Sandelowski et al., 2003; Sandelowski, 2000, 2004; Streubert & Carpenter, 1999; Streubert et al., 2003; van Manen, 1990).

Physical safety is sometimes a consideration when discussing methodological approaches for conducting research (Paterson, Gregory, & Thorne, 1999; Pierce, 1995).The degree of risk was apparent for the researcher when studying certain types of participants, especially in the research interview setting. The area of fieldwork for the current study was in transient neighborhoods with many single-room occupancies, where drugs were used and criminal activity was common.

Neighborhoods that were economically, culturally, or ethnically different from that of the researcher or neighborhoods with whose environment the researcher was not familiar might also pose safety issues for the researcher. The community centers that the researcher considered to recruit participants did not pose any problems in terms of safety concerns since no participants were recruited from that source (Liamputtong, 2007).

There are a number of strategies to assist the researcher to help prevent harm when conducting fieldwork. Planning includes equipping oneself with appropriate communication and alarm devices, maintaining a state of acute awareness, maintaining visibility, preparing for the research venture, interviewing in public places, and conducting research during daylight hours (Paterson et al., 1999). The researcher used these identifying guidelines and principles to develop a safety protocol that reflect elements of safe fieldwork.

Access and Recruitment of the Sample

The cognitive ability of elderly individuals may call for the need of information that is simple to comprehend and interpret. Drennan (2003) identified five barriers to obtaining intended information and came up with a solution. He suggested using cognitive interviewing. Cognitive interviewing involves the use of semi-structured, interviews that are designed to identify problems with questionnaires. Although the technique was developed for quantitative research methodology, the positive aspect of cognitive interviewing is that the data collected by using this method comes from the participant's perspective, not that of the researcher.

Demographic Data

After the participant contacted the researcher by telephone, mail, or email, the researcher collected demographic information. The information collected from the demographic questionnaire was used to determine inclusion of the participant and to obtain statistical information about the participants and is displayed on a table #1, labeled "Demographic Data," in the completed manuscript. The demographic questionnaire was collected for general information about the participants and to determine if the participant was a fit for inclusion in the study (see Appendix J, labeled "Demographic Questionnaire"). Although the technique of the questionnaire was developed for quantitative research methodology to collect demographic data, questionnaires were used and are an important tool to obtain information that was easily obtained and are appropriately used to collect information in a qualitative study (Drennan, 2003).

Inclusion Criteria

Inclusion criteria for participants are as follows. The researcher recruited a volunteer self-referred population of up to 20 participants (Creswell, 1998, 2003, 2005, 2007; Miles & Huberman, 1994; Streubert & Carpenter, 1999; Streubert et al., 2003). For the purposes of this study, a “Black American” is an African American. More specific, a person who by self-definition is a African American but different from self-identified African/Black Americans that have ancestral roots in other countries. Example, individuals of Caribbean, Haitian, Latino, et cetera, may be "Black,: but have different ethnicity than a African/Black American with ancestral root in America from Africa (Bryant, Taylor, Lincoln, Chatters, & Jackson, 2008). the individual, black American described in this research study must have also had their ancestors as slaves in America, The meaning of the word “Black” as a racial designator varies with the context. There are various systems of classification around the world (Shelby, 2002).

The researcher was aware that participants of the Black population might be leery of a researcher’s true intentions (Campinha-Bacote, 2009). The study was limited to participants who agreed to be audiotaped (Degenholtz et al., 2002; Perkins et al., 2002; Waters, 2000).

In this study, a Black American was a person who self-identified himself or herself as Black or African American. The participant must have ancestral roots in Africa. Also, the participants’ ancestors should have slavery roots in the United States.

After discussing the criteria with the researcher, other criteria for participants were discussed. The participant could be male or female and had to be 65 years of age or older (elderly). The potential participants had to be residents of South Florida who had no present known life-threatening or terminal disease.

The individuals had to be cognitively stable, as determined by the researcher during the initial interview, and had to have the ability to make their own decisions. Participants had to have the ability to read and to comprehend the consent form. They needed to understand the nature of the project. People who volunteered may or may not have initiated an AD.

Exclusion Criteria

The purpose of this study was to explore the perceptions of elderly Black Americans. A purposeful sample was necessary to extract information to answer the research question. According to guidelines set by early developers of the qualitative research paradigm, a purposive population allowed the researcher to explore and to portray the full, rich description of the phenomenon under investigation (Miles & Huberman, 1994; Streubert & Carpenter, 1999; Streubert et al., 2003).

Ethical Considerations/Protection of Human Subjects

The initial step in preparing to conduct research is to protect the rights of research participants. The researcher obtained approval to conduct the study from Barry University’s Internal Review Board (IRB) (see IRB documents, Appendices “A, B, and C, Labeled “IRB Documents”). Following IRB approval, recruitment of participants began the research process. After initial contact with the participants, the researcher contacted each intended participant by telephone to set up the first meeting at a mutually agreeable time and place.

Each participant was given a consent form during the initial meeting. IRB confidentiality issues, potential risks, and benefits were discussed with the participant. Clarification and any questions were also addressed at that time (Munhall, 1988). The provision that the participant could drop out of the research, could stop the tape-recording, or refuse to answer certain questions at any time for any reason was reinforced. The researcher may also have chosen to terminate the interview, if any distress, inconsistencies, or research safety became a concern for the researcher or the participant(see Appendix L, labeled “Support Information for Participants”).This was a confidential study. The information provided was held in confidence to the extent permitted by law. Any published results of the research referred to group averages only. No names or other identifying information were used in reference to the study.

A self-assigned pseudonym was used to refer to the participant in reporting the findings of the study. Data was stored in a locked file safe in the researcher's home office. The signed consent forms were kept separate from the data collected by the interview, transcribed material, and/or field notes. The researcher was the only person to collect data.

Data Collection Procedures

Once the participant contacted the researcher, one-on-one interviews were conducted in a mutually agreeable time and place. The participant selected a pseudonym that was listed on the demographic data form. The researcher evaluated if participants fit the inclusion criteria during the initial phone call and again at the beginning of the interviews. At the time of the initial phone contact, the researcher clarified any questions the potential participant had and stated that the interviews would last about one hour.

Data Management and Storage

To assure confidentiality, all data collected was stored on a thumb drive in a locked cabinet in the researcher’s home office. After transcripts were complete and were checked by participants, the audiotapes of the transcripts were destroyed, within four days from the time of transcription. Consent forms are being kept in locked storage separate from other research data, in the researcher's home office. The information was stored according to Barry University’s IRB and will be destroyed within five years after completion of the study.

Instruments/Measures

During the first meeting, questions were answered; the participant read and signed the consent form. A copy of the signed consent form was given to the participant, and a referral was given to the participant. The one-on-one, face-to-face, audiotaped, interviews lasting no more than one hour per session were conducted by the researcher. Data collected from the interview was transcribed by the researcher (See Appendix E, labeled “Transcriptionist Confidentiality Statement”).

Following the interviews, which lasted no more than one hour, the participants were given a $20 gift certificate in appreciation of their time. At the end of the first interview, the participant was invited to review the transcribed materials during a follow-up interview. The invitation was for the participant to confirm the material from the initial interview. For the participants that agreed to a follow-up interview, arrangements were made to hand deliver the transcriptions or send by mail or e-mail for review.

Two weeks after the participant received the transcribed material, the researcher called the participants to arrange a follow-up meeting, with the time, date, and location agreeable to both parties. The follow-up meeting lasted about 15-30 minutes. Recruitment and interviews continued until data saturation occurred. Saturation meant the researcher was confident that no other new information could be gained from additional interviews.

For the interview, the researcher used a opening question (see Appendix F, labeled ”Research Questions“ and Chapter Three) after the demographic data was obtained and after the referral sheet (see Appendix L, labeled “Support Information for the Participant”) was received. Other possible questions were included on the interview guide to prompt answers about the participants perceptions related to Advance Directives and end-of-life care (see Appendix F labeled “Research Questions”) and possible interview questions (see Appendix K labeled, “Interview Guide”).

The researcher used two audiotape devices. The researcher took a journal to take field notes to supplement the data following the interviews. There was no need for exclusion of information used for analysis since none of the participants dropped out.

Research Rigor

Research rigor was maintained as prescribed by the forerunners of qualitative research (Creswell, 1998, 2002, 2005, 2007; Lincoln & Guba, 1985; Sandelowski, et al., 2003; Sandelowski, 2000, 2004; Streubert & Carpenter, 1999; Streubert, Speziale et al., et al., 2003). Trustworthiness represents the extent to which the findings represent reality

(Morse & Field, 1995). Trustworthiness includes the use of credibility, confirmability, dependability, and transferability (Creswell, 1998, 2002, 2005, 2007; Lincoln & Guba, 1985; Morse, 1991; Sandelowski et al., 2003; Sandelowski, 2000, 2004; Streubert & Carpenter, 1999; Streubert et al., 2003). Peer debriefing or member checking was used by reviewing the data interpreted with the researcher's dissertation committee, which includes experts in the method of qualitative inquiry.

The researcher was the lens through which conclusions were derived. The themes that were uncovered originated from the interviews and observations as seen through the researcher's lens. Problems with researcher objectivity continue to plague the rigor in qualitative interpretation. Nurse researchers continue to raise questions about the nature of knowledge (Morse, Penrod, & Hupcey, 2000).

When using a quantitative approach from an empirical positivistic view, the conclusions are drawn from assumptions that only one reality exists with one truth in one world. Qualitative research differs in the sense that multiple realities exist; there are multiple truths and multiple worlds. The researcher is the instrument through which conclusions are drawn and interpreted (Creswell, 1998, 2002, 2005, 2007; Lincoln & Guba, 1985; Morse, 1991; Sandelowski et al., 2003; Sandelowski, 2000, 2004; Streubert & Carpenter, 1999; Streubert et al., 2003).

Truth-value, or internal validity, in quantitative research applies to credibility in the qualitative paradigm. In qualitative research, one method to lessen this threat and enhance creditability of the document also known as authenticating. The researcher authenticated information gathered from the participants (Berg, 1998; Creswell, 1998, 2002, 2005, 2007; Sandelowski et al., 2003; Sandelowski, 2000, 2004; Streubert & Carpenter, 1999; Speziale & Carpenter, 2003; van Manen, 1990).

Credibility

Credibility is something that is attained rather than a process. It can be accomplished by the researcher immersing himself or herself in the data. Credibility can also be obtained by the participant recognizing data as his or her own and validating or authenticating the information. The researcher used authenticating techniques during the entire research process. Member checking and bracketing increased credibility of the intended research. Sandelowski felt that the term credibility was too rigid and inflexible and served an ontological view of only one reality, in the quantitative paradigm (Creswell, 1998, 2002, 2005, 2007; Sandelowski et al., 2003; Sandelowski, 2000, 2004; Streubert & Carpenter, 1999; Speziale & Carpenter, 2003).

A threat to the credibility of the researcher's work can occur when the researcher becomes more confident that the interpretations and conclusions drawn from the data obtained from the participants are correct. The process of adding the researcher's own information, biases, and interpretations provides a possible overweighting of data. These processes add to diminishing the credibility of the research document.

Confirmability

Confirmability is a reverse analysis so to speak, an audit trail (Munhall, 2007). An audit trail can be used to verify researched data. The use of an audit trail is used to confirm that researched data has been scrutinized according to the qualitative process. The audit trail tests for the accuracy of data reduction, analysis, and synthesis. Personal notes and information obtained during bracketing are not part of the confirmable material.

An audit trail is used to support the trustworthiness of the research. The researcher used the research proposal, and documentation of the researched material confirmed the process (Wolf, 2003). Triangulation, member checking, and reflexive research journals are other ways some researchers promote to confirmability (Lincoln & Guba, 1985).

Dependability

Qualitative researchers cannot follow the guidelines used in quantitative research associated with reliability and validity of qualitative-derived research (Leininger & McFarland, 2006). “Reliability” and “validity” are terms that are not associated with issues addressing the creditability of qualitative analysis. The same holds true for dependability. There can be no dependability without credibility. The researcher used credibility checks to establish dependability for the intended research (Guba & Lincoln, 1981; Lincoln & Guba, 1985; Morse, 1991;Sandelowski, 2000; Sandelowski, 1986; Sandelowski et al., 2003; Sandelowski et al., 1997; Streubert & Carpenter, 1999; Streubert et al., 2003).

Transferability

Transferability in qualitative research refers to the “fittingness” of the research(Koch, 1994, 2006; Lincoln & Guba, 2000).The fittingness refers to applying the researched findings to other individuals in similar situations. One advantage of qualitative research is that the researcher is enabled to describe thick, rich, full descriptions of the research data. The fittingness of the perceptions of elderly Black Americans about ADs speaks of the ability transfer the same or similar results when the study is transferred to a different target population group. The transferability of that study increases the credibility of the original study.

The results of the proposed research would not “fit” or could not be applicable to a population of Chinese immigrants in south Florida urban community. The implications for the “fit” are pertinent to the participants and not the researcher (Guba & Lincoln, 1981; Lincoln & Guba, 1985; Morse, 1991; Sandelowski, 2000; Sandelowski, 1986; Sandelowski et al., 2003; Sandelowski et al., 1997; Streubert & Carpenter, 1999; Streubert et al., 2003). Consistency is the concept of auditable ability and describes the ability of the reader to follow the decision trail of the researcher’s development of themes (Guba & Lincoln, 1981; Guba & Lincoln, 1985; Powers & Knapp, 1990).

Data Analysis

An inductive approach was used to evaluate the data collected. The researcher transcribed the data collected within two days of the interview. Analysis was ongoing, with constant comparisons made between participants’ transcriptions (Strauss & Corbin, 1998). The constant-comparison method is one described by Strauss and Corbin (1998) as appropriate for qualitative interviews because the researcher continually compared data to check for the presence of repetitious data. Creswell (2003) has a structured format for the construction of a matrix that leads to emergent themes (see Figure 4, labeled “Data Analysis, and the Inductive Logic of Research”).

Data analysis involved structured strategies are described as follows. The researcher first generated categories of information through a process (open coding); next, categories were selected and positioned in a model (axial coding), and the final step was to elucidate a clear story from the relations of the categories (selective coding). As new data were compared with previous data, different levels of codes, or labels, emerged. The codes were designated as themes.

The purpose of this study, using the exploratory descriptive-research method, explored elderly Black Americans' perceptions of ADs. Data was interpreted through the interpretive data analysis described above. Miles and Huberman (1994)and van Manan (1991) who recommends the use of a post-comment interview sheet as a self-monitoring tool to ensure credibility of the study. The post-comment interview sheet became a part of the researcher's journal. The sheet was used to note aspects of the interview process that provided excitement, surprise, and clarification. The researcher remained responsive to the participants' reactions (Morse, Barrett, Mayan, Olsen, & Spiers, 2002). Data management is the first step in the analysis of data. If data are maintained in an organized, concise manner, it eases the data collection and interpretation process (Streubert & Carpenter, 1999; Streubert et al., 2003). The field notes and the researcher's journal served as the researcher's study codebook to assist the researcher in continuing to monitor and to code during the analysis.

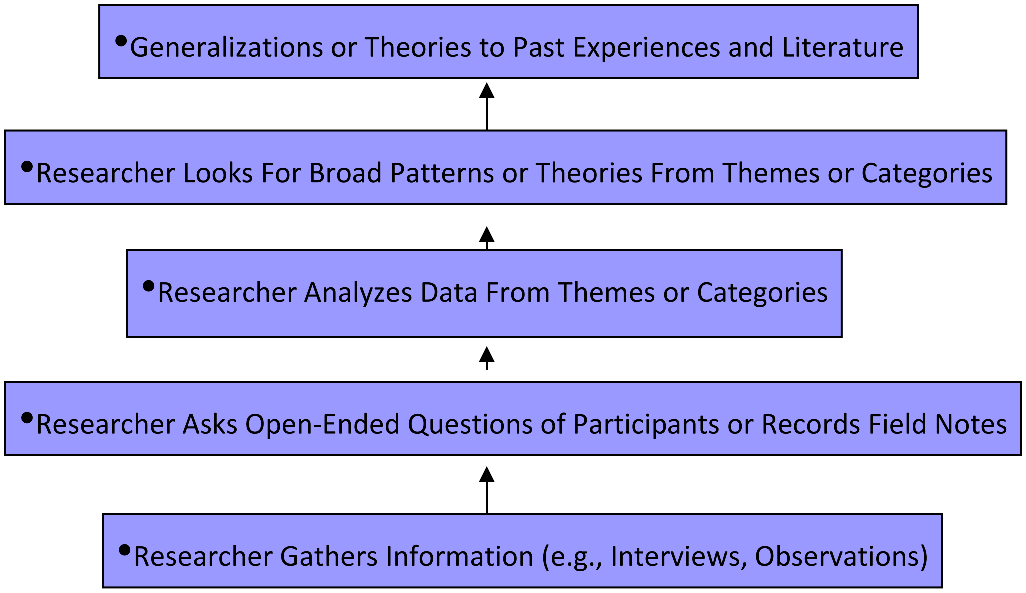


Figure 4.Data analysis and the inductive logic of qualitative research. Creswell, J. (2003). Qualitative Procedures. In J. Creswell *Research design: Qualitative, quantitative, and mixed method approaches*(2nd ed.) (p. 132).Thousand Oaks, CA: Sage.

Chapter Summary

Chapter Three explained the strategies that were used in this qualitative research study to answer the question “What are the perceptions of Black Americans about ADs?” The researcher used a purposeful sample of elderly Black Americans. Participants were recruited from South Florida community centers and churches.

Although there was no direct benefit to participants, the involvement of participants may aid nurses to describe and understand the perceptions of elderly Black Americans about ADs. Ethical implications and considerations were discussed, and IRB documents are included in the dissertation. The participants signed a consent form that stipulates their involvement in the proposed research. Data analysis included data reduction through content analysis to discover emerging themes. The themes that emerged were obtained from the full rich description of the perceptions of elderly Black Americans about ADs.

The researcher utilized the procedures associated with qualitative research rigor to ensure trustworthiness of the data. Credibility, confirmability, dependability, and transferability are all accepted terms that describe procedures to promote trustworthiness of the data. The researcher explained the methods, treatment, and organization of data throughout the research process.

CHAPTER FOUR

Findings of the Inquiry

Introduction

Black Americans are less likely to know about or to complete ADs despite the availability of such preplanned end-of-life care documents (Born et al., 2007: Caraliset al.; Eleazer et al., 1996; Kiely et al., 2001). The elderly Black American population is considered to be a vulnerable group within the United States (de Chesnay, Wharton, & Pamp, 2005). This exploratory qualitative study describes elderly Black Americans' perceptions about Advance Directives (ADs). In the current study, there were a total of nine participants, two men and seven women. In this chapter, a purposeful sample of elderly Black American participants will be described individually using a pseudonym chosen by each participant. After individual participants' are described, excerpts from their interviews will be offered to support the themes that emerged from the data.

The nine participants were all long-standing residents of South Florida, having lived in South Florida for 40 years or more. Participants all resided in traditional "southern black" cultural communities (Roff et al., 2005). Such communities were defined by the researcher as close-knit family neighborhoods perhaps with a neighborhood grocery store nearby.

Families in these communities had a focus on traditional southern cooking, lived in middle-income homes, and usually attended Christian Southern Baptist churches that were often also located in the neighborhood (Hutch et al., 2011). The participants in this study lived in similar communities in South Florida north of Miami (Harris, 2010).

Participants lived in communities that were predominantly African American and were from lowto medium socio-economic status (van Ryn, 2009).

The participants ranged in age from 66 to 88 years old. All of the participants were evaluated by the researcher as cognizant enough to make their own decisions about participating in the research (see Appendix D labeled “IRBProtocol”). Descriptions of each of the Black American’s perceptions about ADs were articulated during one-on-one, face-to-face interviews between the participant and the researcher. All participants were interviewed in their homes at their request. Pseudonyms chosen by the participant were used to protect participant identity. Most of the participants did not complete a high school education. A summary of the demographic data obtained from the group of participants is presented in Table 1 that follows labeled “Demographic Data.”

Table Demographic Information

Table 1

*Participant Demographic Data (*N* = 9)

	N	%
Born in America	9	100
Over 65 years old	9	100
Have an Advance Directive	1	11.1
Female	7	77.7
Male	2	22.2
Married	2	22.2
Single, never married	2	22.2
Widowed	4	44.4
Divorced	1	11.1
Have Dependant Responsibility	1	11.1

*Other demographic information is displayed throughout the document as Figure references

Results from interviews were formulated from nine participants, although 12 participant interviews were conducted. One interview was conducted as a pilot exercise and practice interview to reinforce the basic communication skills needed for effective interviewing and to test the interviewing equipment (Liamputtong, 2007). This first interview was conducted with another PhD graduate student colleague who also planned to use the method of qualitative inquiry for her research.

The practice interview served as a reminder to promote bracketing (Wojnar & Swanson, 2007) and to avoid leading the participant. An attempt to bracket involved the researcher's acknowledgement of feelings about end-of-life issues and ADs through journaling, discussion with peers, and discussion with her committee members. Thus, the researcher sought to set aside values and biases about ADs during the interview process with the participants.

The practice of suspending assumptions during the interview and contemplation activities was also suggested by Munhall (2007) and is called "decentering." Such activities were interpreted by the researcher as similar or possibly the same as the concept of bracketing suggested by Creswell (1998, 2002, 2005, 2007) and others (Barroso, & Volis, 2003; Miles & Huberman, 1994; Sandelowski, 2000, 2004; Streubert & Carpenter, 1999; Streubert et al., 2003; van Manen, 1990, 2002).

The practice interview with the PhD student colleague involved asking the same questions the researcher planned to use during subsequent interviews. In the practice interview, the researcher employed the same techniques as described by Miles and Huberman (1991) and included listening to the colleague's descriptions of an experience, interpreting the meaning of the experience, and checking for the accuracy and proximity of meaning of each statement. Two additional interviews (numbers 11 and 12) were conducted to validate the themes and promote rigor of the research (Speziale and Carpenter, 2003). These additional interviews served to promote dependability, credibility, and confirmability of the researcher's conclusions that saturation had been achieved (Speziale & Carpenter, 2003).

Participants' lack of a formal education became evident by the participants' difficulties in communicating verbally a description of their perceptions about ADs. However, similar (cultural)understandings or belief systems (Campinha-Bacote, 2009) between the participants and the researcher became apparent as the interviews progressed. For example, the researcher understood the culture and belief system of the participants since she had been raised in a similar cultural background. Therefore, even when the participants had difficulty expressing their perceptions, the researcher was able to ask follow-up questions that appeared to assist the participants to express themselves more fully about the AD/end-of-life care topic that appeared to be difficult for the participants to explore.

Interviews, Transcriptions, and Interpretations

What are elderly Black Americans' perceptions about Advance Directives (ADs)? Participants' perceptions were described as perceptions emerged from the one-on-one interviews and researcher's field notes. Their perceptions were transcribed verbatim by the researcher. This self-transcription assisted the researcher to become more immersed in the participants' words. Their words were then compared to the words of other participants until key concepts and phrases were identified that were similar (Miles & Huberman, 1994; Sandelowski, 2004).

van Manen (2004) describes the interpretive process as the world of natural attitude of everyday life. The interpretive process was mirrored as the participant and researcher sought to clarify together answers to the interview questions. The researcher considered herself an “insider “or an “emic” participant due to her cultural similarities between the researcher and the participants (Leininger, 2002).

The researcher was a Black American and was raised in a southern Black cultural environment with parents who were working middle class and similar to the participants in the study (Leininger, 2002). The themes that emerged through the exploratory dialogue with the study participants and the researcher were enhanced by field notes written following each interview and additional researcher’s notes during the transcription phase. The researcher came to appreciate and support the process of self-transcription. Self-transcription helped the researcher to re-live and re-interpret each interview.

The self-transcription process allowed the researcher to gain additional meaning regarding participants’ nuances of their life experience as they described their perceptions about ADs and/advanced end-of-life care planning. The personal stories provided by the participants clarified the particular while suggesting the existence of and a connection to the universal (Creswell, 2007; Ferrell-Rollins, 2010). For example, Ferrell-Rollins has suggested that there are many distinctions about death that are both particular to the individual but that are also universal among all persons as they die.

Sandelowski’s (2004) qualitative inquiry approach was used in combination with the use of the method of Miles and Huberman (1994) to organize data and identify themes. Sandelowski suggested a methodology approach that allowed the researcher to explore and describe participant's perceptions. Sandelowski's method and Miles and Huberman's matrix method was used as a means of qualitative data analysis, data reduction, and construction of a picture of the perceptions through the emergence of themes from elderly Black Americans about preplanned end-of-life care.

Content analysis of the interview sessions on the perceptions of elderly Black Americans about ADs was used to assist the researcher to identify potential themes. After transcription, the researcher read interviews multiple times, making notes and writing down key phrases and possible differences and similarities. Color coding was used (matrix formation). As similar words and phrases were repeated, themes emerged. The themes that emerged during the process of content analysis and matrix formations were repetitive in the majority of the participants.

Brief descriptions of each participant were given to give the reader a portrait of the participant and included a description of the neighborhood and environment where the interviews occurred. The researcher described the participants as verbalized by participants and interpreted by the researcher. All participants were interviewed in their homes. Throughout all descriptions about the participants, they were identified by their pseudonyms only. Examples from different participants are illustrated and discussed within each of the themes.

The Interviews

The interviews lasted approximately one hour with the exception of one interview. Paul's interview lasted 30 minutes. Paul appeared annoyed about the topic when he realized what we would be discussing but agreed to continue. The researcher included Paul in the analysis as his reluctance to discuss the possibility of death was very pronounced in his responses. His responses may reflect feelings of others that were not research participants. Munhall (1988) has noted that the qualitative researcher should be sensitive to those participants who do not express the feelings of others but may provide a more complete picture of the concept of interest. The researcher began the interviews in accordance with the IRB protocol.

The researcher gave participants an opportunity to ask further questions and reviewed consent forms before beginning the interview. At no time did the researcher feel physically threatened within each participant's environment. The researcher was conscious of the necessity to be vigilant about the environment at all times (Paterson et al., 1999; Pierce, 1995).

The formal interview began when the researcher asked an initial grand tour question, "Can you tell me what Advance Directive is?" The researcher recognized that this question could be answered yes or no. A "yes or no" possible response to a grand tour or most questions is not, according to Berg (1998), ideal to begin a qualitative interview. However, after the review of literature and the researcher's practice interview and through discussion with the researcher's chair (S. Walsh, personal communication, June 10, 2010), the researcher decided she would first need to establish if the participants knew the terminology "Advance Directive. "

Description of the Participants

Bobbie. Bobbie was the eldest of the participants in this study 89 years old. Bobbie's life is very interesting. She married very young at 17. Bobbie's formal education consisted of a fourth-grade grammar level. Bobbie had two children when she married. Her husband was 35 years her elder; they had 12 children together. She lived in an old Ft. Lauderdale area known as Sistrunk Quarters. Sistrunk Quarters is now under renovation, allotted millions of dollars for historical rejuvenation. Bobbie lived in a one-bedroom home that the researcher would describe as shabby (peeling paint, in need of repair) along Old Dixie Highway in Ft. Lauderdale, Florida. Most shacks that were previously a part of Sistrunk Quarters have all been torn down, although some remain in Pompono Beach and on Broward Boulevard. The existing shacks remain for historical reasons. Sistrunk Quarters is where most Blacks lived during the early 50s (see Figures 3 and 4). Doc Sistrunk was a notable leader within the established Black community of Sistrunk Quarters. Bobbie said Doc Sistrunk delivered all of her children.

Bobbie’s husband was a very light-skinned migrant worker foreman. I mention the color of his skin because his light skin color may have influenced his elevated position as a migrant farmer foreman. Bobbie shared one part of history about her husband that helped the researcher to understand Bobbie’s current living status. Bobbie’s husband died at a young age, leaving Bobbie to raise their 12 children. The landowner and boss of Bobbie’s husband died prior to Bobbie’s husband. The contents of the landowner’s will stated that he wanted to give Bobbie’s husband12 acres of land. The 12 acres represented one acre for each of Bobbie and her husband’s children. The astonishing thing about this story is the land was located in Plantation, Florida and today is worth millions. The landowner’s daughter contested her father’s will and won. Thus, Bobbie and her husband’s children never received any land.

Bobbie now lives on a low-income salary supplemented with Social Security. Bobbie stated that when the landowner’s daughter contested the will, Bobbie did not have the money or the means to pursue any legal retaliation about the dispute over the property. I asked Bobbie if she retained any documents from the incident, and Bobbie replied, “No, it was a terrible thing.” Yet, Bobbie is able to live on her own and is self-sufficient.   Bobbie is also retired from a hospital where she spent over 35 years as a patient care assistant (see figures 5 and 6).

James Franklin Sistrunk was born in Midway, Florida (near Tallahassee) in 1891.

He graduated from MeHarry Medical College, in Nashville, Tennessee in 1919. He later served in World War I before relocating to Dunnellon, Florida to practice medicine.

Dr. Sistrunk moved to Fort Lauderdale in April, 1922. Although he was a qualified surgeon, he was not allowed to perform surgical procedures in white hospitals.

In 1938 he joined Dr. Von D. Mizell to establish Fort Lauderdale’s first medical facility for blacks, Provident Hospital. He is credited with delivering over 5,000 babies during his 44 years of practice. Throughout Broward County, Dr. Sistrunk would make house calls and assist those who were financially strained.

Northwest Sixth Street in Fort Lauderdale bears his name, "Sistrunk Boulevard." In addition, a bridge over the north fork on Northwest Sixth Street is named the "J. F. Sistrunk Bridge."

Dr. Sistrunk died on March 20, 1966. He is still honored today, every February, with The Sistrunk Festival, which runs along the boulevard that bears his name, in the heart of Broward's oldest black enclave, the Sistrunk district.

Figure 5. Doc Sistrunk, 1891-1966.*Photograph Retrieved January 10, 2012, from*: **http://sistrunkfestival.org/**

TRUSTEE BOARD OF PROVIDENT HOSPITAL

Figure 6.Doc Sistrunk and Provident Hospital. ***Photograph Retrieved January 10, 2012,   from***: http://sistrunkfestival.org/

Georgia. She is an88-year-old woman who lives with her son, daughter-in-law, and granddaughter (18 years old). Georgia completed a Master's degree and worked 33 years as a teacher. She was forced to go to work full-time when her husband had a massive stroke at the age of 47. Georgia attends a senior citizen day care program during the week that keeps her active and occupied during the day. Georgia's family members who she lives with work or attend school during the day. The researcher has lived across the street from her for over 12 years but never knew her before Georgia agreed to become involved in this research. The researcher has formed a very close relationship with her over the course of this research

Paul. Paul is a 75-year-old male and one of the two male participants in this study. Paul attended grammar school but never completed high school. Paul was a masonry laborer and exhibited an attitude of pride in the work he produces. Now Paul suffers with chronic back pain due to the many years of lifting heavy stones and bricks, necessary elements of his trade. The researcher surmised that Paul might have labored with contractors that did not register Paul as an employee, and therefore, Paul was not able to reap the benefits from his decades of work.

Paul resides with one of his daughters and lives a simple life. Paul shares his home with his daughter. The researcher was not sure exactly which one is the owner or if both own the property. The property is in a low socio-economic, depressed area of Ft. Lauderdale. In the yard of the home where Paul lives, there were three elderly men sitting around a table in the backyard, drinking beer, smoking, and playing cards. At no time did the researcher feel any negative vibes by the environment she was in. The other elderly gentlemen were very gracious when introduced by Paul. Paul said he just "hangs around" during the day, explaining, "There ain't [*sic*] too much I can do with dis [*sic*] old back." It was evident to the researcher how debilitating Paul's back pain must be by the way Paul slowly made his way into the house to begin the interview.

Mr. Robert Lee. Mr. Robert Lee, one of the two male participants in this study, lives alone. The researcher used the term "Mr." as she reflected on the robust way the participant declared his pseudonym. Mr. Robert Lee never married and is now 73 years old. He spent most of his working life in New York City. Mr. Robert Lee was an entertainer most of his adult life. He was a member of a band and played the trumpet. The researcher could feel the excitement and joy when he would talk about the "good old days" and the times that he had as a band member. He now lives a simple life working part-time as a janitor.

Mr. Robert Lee's home was a small efficiency apartment behind the New River, in Ft. Lauderdale, Florida. On approach to Mr. Robert Lee's apartment, the researcher could smell the musty, smoky hallways of the 12-story apartment building. The smell reminded the researcher of the "hole in the wall" jazz clubs located in Harlem, NY in the '70s, in New York City. Mr. Robert Lee resided in a building that is for low-income senior citizen tenants. Mr. Robert Lee appears to be a "happy-go-lucky" man, smiling, joking, and telling of his earlier life. His affect reminded me of a "big Daddy Cane." Daddy Cane is a character from the disco era. He essentially looked like a pimp. Daddy Cane wore his leopard hat, leopard suit, and matching cane.

The researcher could imagine Mr. Robert Lee in his suit, large-brimmed hat, patent leather Stacey Adams to match, and of course a cane. Mr. Robert Lee appears to be the type of guy who enjoys life on a day-by-day basis. He has a sister who lives close by in Ft. Lauderdale. Mr. Robert Lee graduated from high school. Mr. Robert Lee goes to the doctor on a regular basis for his blood pressure, kidneys, and other “things” as he says; he has Medicare for his medical insurance.

Constance. Constance is a 74-year old-woman who never married had two children. Tragically, her oldest son was killed 10 years ago. He was in his 40s. Her daughter has cerebral palsy and therefore is considered developmentally disabled. Constance is the sole caregiver for her disabled daughter. She graduated from high school. She worked as a hostess in the doctor’s dining room at an area hospital for over 25 years.

Constance maintains a home that she has lived in for over 30 years. The home is located in a well-established Ft. Lauderdale neighborhood with mostly Black American residents. She has strong ties with her religion and professes it in much of her speaking. She often adds “Thank God or thanks be to God, and only for the blessings of God.” She attends religious celebrations every week. She said she is financially secure; she lives off her retirement income, supplemented with Social Security benefits. Constance has been plagued with a multitude of medical problems for the past three years that have required her to have several surgeries. Constance has Medicare and supplemental health insurance. The additional health insurance policy she has is one of her retirement benefits.

Emma. Emma is a 69-year-old female. She graduated from high school and began college but dropped out of school when she became pregnant. She married and began her family. She worked over 35 years in the garment industry. She is still married and retired. She stated she is enjoying retired life with her family. Emma said she worked hard all of her life, and it is time to enjoy it. She is very much involved in her grandchildren's' lives, and they visit her just about every day. Emma's husband is also retired and is active around the house always "fixin' [*sic*] up stuff," as Emma puts it.

Emma said she is a senior member in her church and attends services on a regular basis. She involves her grandchildren in church activities as she said "to keep them out of trouble." Emma's home is very clean and nicely decorated with pictures, color-coordinated furniture, and personal items displayed on tables. She lives in a middle-class neighborhood, where she has lived for over 35 years.

Emma and her husband go to the doctor on a regular basis, and both have Medicare and other health insurance policies from their retirement. The researcher noted how close she was with her grandchildren. Her grandchildren were in the house when the researcher arrived for the interview. She was considerate enough to ask the children to go outside while we (the researcher and Emma) conducted the interview. The researcher noted how polite and respectful the grandchildren were to their grandmother. The researcher was impressed with the grandchildren's' manners.

Marie. She is a 68-year-old female who has been widowed for three years. Marie is a particularly interesting participant due to the fact that she suffers from a multitude of chronic illnesses stemming from her diabetes. Marie now has renal failure. She must spend three days a week at a local dialysis center. To complicate her life, Marie also suffers with diabetic retinopathy.

Due to the comorbidity of multiple illnesses, Marie visits her doctors and clinics on a routine basis. She never worked outside her home and therefore lives on her husband's Social Security benefits. She said when she was able she would take in children during the day, like a day care, to help supplement her husband's low income, which was just above the poverty level (Department of Health and Human Services Federal Register, 2011). She receives Medicare insurance to take care of her multiple illnesses. Marie's home is small and cramped. It is part of a one-bedroom duplex in an undesirable, timeworn (houses in need of paint/repair) area of Ft. Lauderdale. Although the area she lived in was considered to be a "rough area," the researcher at no time felt she was in any danger. The researcher believed that Marie felt isolated and alone. Marie stated she has a stepson who is the closest one to her. Marie said she does not get out much because of her illnesses. She does not drive, and her illnesses limit her ability to get around. She said her in-laws stay in touch with her by telephone, but she does not see them.

Laree. She was one of the youngest participants at 67 years old. She did not complete a high school education, and her lack of education was evident in her communication with the researcher. She is divorced. Laree shares a very close relationship with her 34-year-old daughter she lives with and depends on her for financial and other support. Laree and her daughter share a simple two-bedroom condo in an adult community of south Florida.

Laree is creative and has a talent of turning things that other people would discard into beautiful decorative pieces. She was excited to show the researcher items that she has rejuvenated into finely crafted pieces of art. The researcher noted Laree's art work displayed around her home. She never attained any useful employment skills, working menial jobs for short periods of time that did not sustain any long-term benefits. Laree now able to collect Social Security based on her work history. Social Security is her solitary means of support.

Betty. She was a pleasant 66-year-old woman and one of the youngest participants in this study. She graduated from high school and completed one semester of college. She said she had intentions to return to college, but as Betty said, “It just didn’t happen." In Betty's voice and, as a result, the researcher felt she needed to probe. Betty replied to the researcher's probe, “It did not seem important at the time, and I never made the time to do it.”

Betty is divorced and spent most of her adult working career as a medical record technologist. Betty had spent the past 23 years working in that department at a hospital in Ft. Lauderdale. She is now retired. She had a persona about her depicting that she “had it all together.” The researcher made note of Betty’s home. The home was very nicely decorated, and the researcher felt reflected a sense of who she was. Betty spoke proudly of her ability to enjoy her retirement, doing the things she always wanted to, and of her financial independence.

Betty lives with her daughter and two of her daughter’s children. She said her daughter recently divorced, and this was Betty’s way of helping them out. Betty said since she has the time, she donates some time serving at the homeless shelter on a food line. Betty expressed a sense of fulfillment as she spoke about the times she gives at the shelter. Betty has her retirement income, and she said she started collecting Social Security. Betty said; “I started taking my Social Security now, instead of waiting until I am 68, because I might not be around then.” She goes to her doctor on a regular basis for her high blood pressure and high triglycerides. She attributes her illness to genetically linked diseases.

Betty expressed a sense of well-being when she talked about her illnesses. She was quick to let the researcher know it was genetics, not her lifestyle that has caused her illnesses. Betty said she wanted to get the enjoyment out of life that she now had the time to appreciate it. The researcher felt very comfortable in Betty’s home (see figures 7 and and 9).

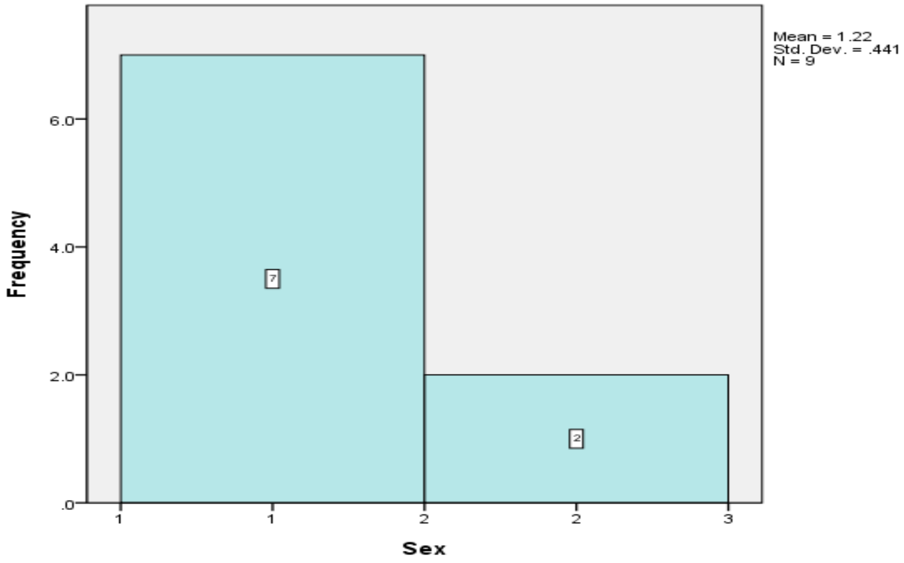


Figure 7.The participants' sex.

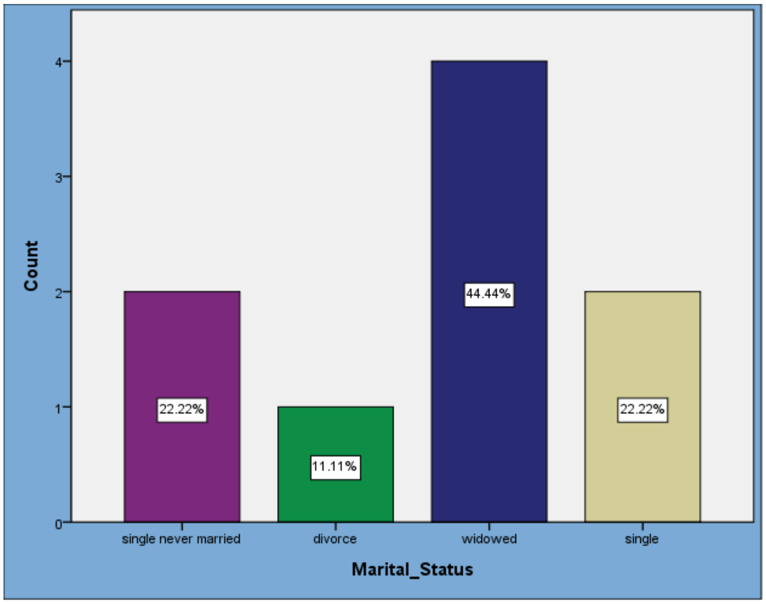


Figure 8.The participants' marital status.

Themes

Educational Deficit

The researcher evaluated the interview data and identified “educational deficit” as the theme that was most predominant throughout the interviews. Knowledge about ADs was consistently absent in seven out of nine interviews. Two participants had some knowledge about Ads, as they stated with some accuracy what the words “Advance Directive” meant. The remaining seven participants claimed they knew what an “Advance Directive” was. However, when the researcher asked; “Can you tell me what an Advance Directive is?,” they could not answer. Additionally, these seven participants were not able to communicate any specific planning that they or their family members had discussed regarding end-of-life care.

The researcher will first describe two participants who did not fit under the theme of educational deficit. These participants, Betty and Constance, were different from all the others as they had some knowledge about the concept and meaning of the words, Advance Directives. Since they did have knowledge about ADs, the researcher discussed the depth of their knowledge before describing the knowledge deficit of the remaining seven participants.

The researcher has already discussed that Betty attended one semester of college. Her history of employment in hospitals in medical records may have also provided her with the knowledge to comprehend the research question about her perceptions of ADs. Therefore, she had knowledge of the concept of ADs when compared to the other participants. Betty replied, “O.K. An Advance Directive is when, ah, you go to the hospital and you don’t want anyone to resuscitate you.”

For elaboration, I asked Betty to explain what she meant by “resuscitate.” Betty replied, “Say for instance you were just, uh, and just don’t want anybody to give you anything to prolong your life.” Betty portrayed herself as an educated elderly Black American female who spent 30 years working in a hospital and is now retired. She worked in Medical Records, which probably enhanced her knowledge about ADs. Throughout the interviews, the researcher continued to explore the work experiences of the participants as the researcher believed participants’ employment may have added to the participants’ knowledge about ADs.

Constance, the participant with the disabled daughter, said she was well aware of the meaning of an AD. She was emphatic about having “things in order” for her daughter’s sake. She spoke at a very low tone throughout the interview. She continually looked over towards her daughter in a way that made me feel she did not want her daughter to know what we were discussing. It was difficult to hear her at times. The television was on, and Constance’s brother was watching a football game.

Although Constance was knowledgeable about an AD, she had not completed an AD. Her interpretation of an AD was: “An Advance Directive is something that if something was to happen to me and I can’t give the permission or whatever for the care, I have someone to umm that has the authority to do that.”

Constance said, “Yes, I just got those papers, I just haven’t set [*sic*] down and fill them out, and a because of the condition I’m in and the condition she’s in” (directing her eyes at her daughter who was sitting in the same room watching TV). The daughter appeared to have no interest in the conversation between the researcher and her mother. The daughter was a high school graduate.

Constance, like Betty, had experience working in hospitals. She worked in the hospital in the doctor’s dining room for over 30 years and is now retired. She had no recollection of anyone approaching her or asking her if she had an AD. Her lack of recollection about ADs was surprising, as Constance had recently undergone four surgeries in the past two years that required her to be hospitalized. She stated recently husband of one of her friends had just “passed.” A representative from the funeral home met with Constance and the friend prior to the death of the friend’s husband. This meeting took place at the home of Constance. Constance said that the funeral home representative did speak to them about an AD/LW. This incident was how Constance was introduced to the concept of AD documents.

Laree in her sixties was not well-educated. When Laree was asked if she had an AD, Laree said she was given “the papers” at the doctor's office. Laree stated she never filled out the papers or even looked at them. Laree said no one ever followed up with her the disposition of those documents. As the interview proceeded with Laree, she explained an AD as “Ah, the certain kind of care that I would like to have if I am unable to speak for myself.” She was only able to provide that explanation after the researcher clarified what an AD was. Laree says if something were to happen and she was unable to speak for herself, she would expect her daughter to “take care of everything.” When Laree was asked if she had ever communicated those feelings with her daughter, Laree replied:

> If I get to the point I can’t speak for myself I would tell her (Laree’s daughter) ahead of time, we will sit down and say, ‘Ok now if anything happens to me, that I can talk or speak for myself, or make no decisions.’

Laree continued with:

> I want you (Laree’s daughter) to make that, that, that I can’t[*sic*], that I am really taken care of right, and seeing that I am being [*sic*] getting the right kind of medicine or medications, you know the right help for me , for whatever the illness is for me."

Although Laree expressed what she would do, it was only after much communication with the researcher. Laree said she would sit down with her daughter before anything happened to her “ahead of time” but had not sat down with her daughter and expressed these sentiments at the time of the interview. The researcher thought this was important information that Laree would address this issue at a later time.

Georgia was asked if she had an AD; she replied, “yes.”She said she filed those papers with her lawyer and thought an AD was part of her will. I asked Georgia “What was in her AD?” She replied, “I really haven’t read it. You know it’s something that is there and I know it’s there, but I never really sat down and read it; isn’t that awful?”

Although Georgia had an AD, she was not sure if the types of treatments she may or may not want were included in the AD document. During the interview, Georgia made an unexpected request of me. She asked that the researcher read Georgia’s AD. I agreed and reviewed the items in Georgia's AD that included those key elements of what Georgia would or not want included in her AD. Georgia said she learned important information revealed to her during my review of her AD with her. The additional information that I gave to Georgia was not requested by others, so such an activity was not present in any other interviews. The researcher’s decision about agreeing to Georgia’s request to review her AD with her will be discussed further in Chapter Five.

The researcher expected that due to Bobbie’s work history and involvement in the medical field, she might have increased her knowledge about ADs. Bobbie’s answers were typical of those participants who thought they knew about ADs but did not. Typically most of the participants answered with statements such as Bobbie, “No, no, not advanced…” or “you mean something that would say where my property goes to?”

Emma admitted without hesitation that she was unaware of the meaning of Advance Directives or anything associated with them. She had a sister that “passed” away in the hospital. She said she cannot recollect any particulars other than her sister had a stroke. She was involved in her sister’s terminal care even though her sister did have a husband and three children. Emma’s sister remained comatose for two days. Emma stated that after two days in the hospital on a breathing machine, the doctors called a family meeting to discuss the Emma’s sister’s prognosis.

The doctors told the family that Emma's sister would never recover or be her former self. Emma said: “The doctors asked us if my sister had any papers or had discussed with family anything pertaining to any medical conditions that may leave her sister in the condition that she is now.” No one in the family had any information like that. The researcher thought that Emma’s facial expression showed deep regret.

The doctors asked the family to consider withdrawing life-support treatment for Emma’s sister based on her condition. She said, “We met that night me, my sister’s husband, and my sister’s three kids.” She continued, “All of us together decided to go ahead with the doctors’ suggestions." They knew Emma's sister would not want to live that way. She was deeply emotional, teary eyed, and slow in deliberating over the event when discussing how her sister died and how unexpected the death was.

Mr. Robert Lee goes to the doctor on a regular basis for his blood pressure, kidneys, and other “things” as he says. He has Medicare for his medical insurance. When the researcher asked Mr. Robert Lee if he knew what an Advance Directive, Living Will, or any document that would let the doctors know how to take care of him if he were unable to speak for himself, he distinctly said no.” The researcher attempted to probe Mr. Robert Lee by asking several follow-up questions to discover Mr. Robert Lee’s perceptions about ADs or any information that he might have received about end-of-life documents. The researcher said, “Maybe you have heard about ADs at a hospital, at your doctor’s office, or in any meetings or conversations with others that live within his apartment complex.”

Although Mr. Robert Lee insisted that he had no idea about what an AD was, the researcher continued to discuss the topic to try and uncover any knowledge that he may have about ADs or advance end-of-life care planning. The researcher asked Mr. Robert Lee if he had any close relative that “passed away” while in the hospital. He could not recollect any close person that “passed” while hospitalized. His lifestyle and carefree demeanor suggested to the researcher that his lack of knowledge about ADs may be attributed to his attitude about death and dying.

Mr. Robert Lee appeared to have the same attitude about dying as how he lives life on a day-to-day basis, with no thought or worries about the future. Spiritual and religious faith provides powerful support for grief for the African American culture (Frazier, Mintz, & Mobley, 2005).   The spirituality of the Black American is discussed as a theme further in Chapter Four and in Chapter Five.

Paul spends most of his day with friends similar to his age and stage in life, “sitting around, shooting the bull,” an ebonic expression used within the Black American culture (Baugh, 2000). Paul by no means knew what an AD was or anything connected with end-of-life planning. The mood of the interview depicted an eerie atmosphere, not one of fear but almost a spiritual ambiance. Paul made it clear. “We don't talk about that. You know what I mean, we just don't talk about that” (looking deep and intense into the researcher's eyes). That statement by Paul only spawned more interest about Paul’s perceptions about any advance end-of-life care planning.

The researcher took a different approach to try and trigger any information from Paul on the subject of advance end-of-life care planning. The researcher asked Paul if he had any person close to him “passed” away in the hospital. Surprisingly enough, Paul had a daughter who had “that coughing thing” and died in a long-term care facility. Paul’s daughter was in her thirties. He was the closest relative to his daughter. The researcher ascertained that Paul’s daughter passed away with HIV-AIDS, probably pneumocystis pneumonia. He never directly called his daughter's illness by that name, but the researcher was able to define the illness during the course of the interview.

The researcher probed Paul for information pertaining to removing life-support equipment or the withdrawal of treatment, based on the state of Paul’s daughter’s illness. Paul could not recall his daughter’s doctors approaching Paul and asking to “stop” treating her or remove any “breathing machines.” He could not remember if his daughter was being fed artificially or if she was even conscious. Paul was completely unaware of any type of AD that may/or may not have impacted his daughter’s care. He continued to express his disinterest in the concept of ADs, and the interview ended after 30 minutes.

Marie was the participant that had multiple co-morbidities but had no knowledge about ADs even though she was on dialysis. When the researcher asked Marie if she had any knowledge about Advance Directives or what it was, Marie said, “No.” The researcher restated the question and asked Marie if she had heard anything about living wills or advance end-of-life care planning from any of her medical care providers. Again Marie said, “No.”

Trust and distrust of the medical system was not a supportive factor for these participants. The researcher included trust/distrust in her interpretations because trust/distrust has been a viable predictor in the past, as barriers against using ADs by African Americans (Baldwin et al., 1990; Belcher et al., 2006; Blackford, 1990;Coffman, 2004; Katz et al., 2006; Kelly& Floyd, 2001). Trust/distrust of the medical system was evaluated as a sub-theme.

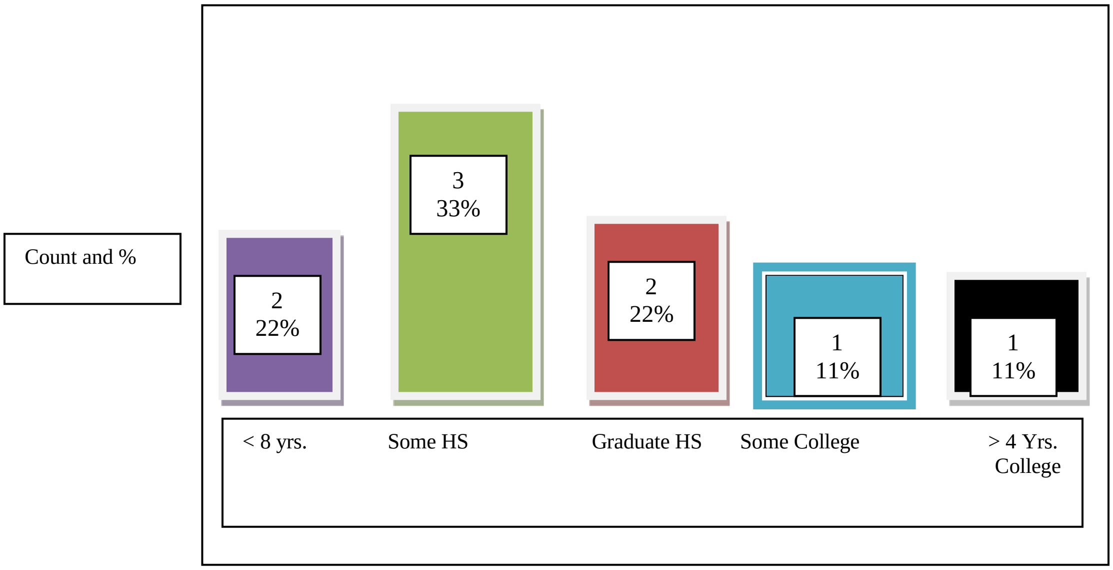


Figure 9.The participants' educational level by percent.

Financial/Other Burdens

The participants all spoke of burdens they did not want to leave to their families. Yet, they could not relate to end-of-life discussions that would create burdens of their loved ones when confronted with a situation where a person was likely to die. Georgia had completed an AD but did not understand the meaning of an AD. Bobbie and Laree had some notion of what ADs were. Constance was engrossed with making sure her daughter would not be financially struggling if Constance was to pass before her. Betty was “too young and had plenty of time to get that taken care of.”

Robert and Paul both appeared not to care about what happened to them when they died but knew they “would be taken care of.”Lastly, there was Marie who was still grieving her husband’s death, three years ago. Emma had experienced the death of her sister and continued to agonize with the fact her sister’s illness was sudden, devastating, and totally unexpected. The family could only guess what her sister may have wanted; the sister was left in a persistent vegetative state for the remainder of her life.

Expressions of concern about financial burden that loved ones might have to bear at time of death were a prevalent and ongoing theme during the interviews. Financial burden was expressed in terms of worry about leaving large medical bills and funeral and burial expenses, putting affairs in order, and leaving other financial burdens to family members and/or loved ones. Worry about ominous financial burden was profound in many of the voices of the participants as they spoke of the useless waste and fatalistic approach to keeping one’s body alive on machines and other medical devices.

Participants spoke of the burden that family members would have to sustain, “if things were not taken care of properly.” The phrase, “if things were not taken care of roperly," spoken by one of the participants, summarized the anxiety the participants expressed in such terms of how they made sure their final needs would not cause any hardships for the ones left behind. While most of the participants spoke highly about taking care of the financial burdens, only one of the participants, Georgia, had any sense of the multitude of other burdens their loved ones would be left with.

When the researcher asked Marie if anyone close to her died in the hospital, that question led to a dialogue that uncovered emotional burdens that Marie had endured. Her husband Joseph/Joe (a pseudonym assigned to the husband by the researcher) had a fear of financial burdens, and his fear may have contributed to Marie's psychological or emotional burdens. Marie said her husband died three years ago of lung cancer. Marie's husband Joseph smoked four packs of cigarettes a day until he was too close death to physically smoke anymore.

"Joseph never went to the doctor," Marie said. "Joseph knew there was no treatment for what he had." Marie sadly stated, "That was as far as any talk about Joseph went." Marie and Joseph knew he was going to die. Marie said, "Joe knew he was very sick, but he wouldn't go to the doctor." The researcher asked Marie if her husband had health insurance. Marie said, "Joe had some medical insurance, and he was a veteran, but Joseph felt what he was sick with would cost much more than he had insurance or money to pay for." She said she asked Joe go to the doctor many times, but he wouldn't.

Marie said, "Joe wanted to be cremated. Joe was a veteran so his final costs would be taken care of." It was heart wrenching to sit with Marie as she explained the last days of Joe's life. Marie said, "I died with Joe during the end. I felt so helpless, like there was something I could do to make him more comfortable." Marie wanted to call 911 when Joe was vomiting blood two days before he died. Joe forbade Marie to call anyone to assist in his terminal care, and so Joseph died.

Marie's conversation continued as if she needed to vent her feelings about the last days of her husband's life. Even though Marie had continual involvement with the medical community and her husband had a terminal illness, she said she was never asked about, nor had anyone mentioned, "papers" such as a LW or AD. Her last statement was, "Joseph worked up until two days before he died." The researcher sensed the statement was a testament to Joseph's ultimate sacrifice for Marie.

Paul was one of the two male participants not interested in talking about death or ADs. Paul was the participant that suffered from chronic back pain. He had a daughter that "passed" in the hospital with that "coughing thing." Paul was emphatic when he expressed he would not let his daughter go through "dat" [*sic*]. He said "I made sure I had enough insurance to take care of me, when it is my time to go." The researcher interpreted "take care of me" to mean Paul's financial needs when he died. Paul was the participant that was insistent in his opinion that he did not want to speak about death. Paul made other remarks during the course of the interview suggesting that he did not have much, but he was able to take care of himself.

Bobbie was exuberant as she told her story about when she goes to "meet her maker." Bobbie was not fearful, almost a sense of jubilation as she talked about her time to pass. Bobbie said:

> I worked hard all my life, I growned [*sic*] 12 children. My husband died young and he left me with all these childrens [*sic*]. You know I worked as a nurse, a nurse's aide. I get a retirement now; I take care of myself.

Bobbie said, “I even help them out sometimes.” The researcher asked Bobbie who she meant by “them.” Bobbie said:

> My children, grandchildren, and great grand childrens’[*sic*]. When the Lord is ready for me, I am ready to go. I don’t want to be hooked up to no machines or anything like that, it costs too much money. I don’t want my daughters to worry about taking care of me. I know my daughters will know how to take care of everything you know financial and everything”

These were only a few of many excerpts Bobbie spoke about in reference to being a financial burden or not being able to take care of her, and Bobbie trying to prevent others being burdened because of her.

Laree never stayed in one job for a substantial amount of time. Laree, now retired, says she is very close to a 30-year-old daughter. She lives a simple life. Laree does not have a lot of material goods, but her morals and values are embedded deeply within her traits. Her beliefs are depicted as she discussed end-of-life concerns during the interview. For example, Laree understood the financial aspect of keeping one alive when the doctors say there is nothing else that can be done.

Laree had a brother-in-law who was hospitalized for an extended period of time. Her sister-in-law decided to withdraw all life support. Laree told the researcher how her sister was always talking about the fact she would never be able to pay all of her husband’s medical bills. Her sister is now burdened with hospital bills as she struggles to live without her husband.

The researcher perceived that Laree may have been trying to prevent the emotional burden that end-of-life care might cause family members. Laree said, “I would never want my daughter to have to be responsible for me." However, Laree did not have an AD. If an AD had been signed and discussed, the emotional burden she was trying to prevent may have been lessened. Laree was the one participant that said, "There is always hope, even when the doctors say there ain't [*sic*] nothing else that can be done." The researcher attempted to probe so Laree would elaborate on her conflicting views. She evaded the dilemma by elevating the concept of "always hope" to a spiritual level and minimizing the financial aspect of burden to a mortal concern. The researcher was unable to ascertain how or if Laree would ever address or attempt to solve the conflict. The researcher asked Laree to think about how she could resolve the dilemma before it became a concern for Laree or her daughter.

Georgia was not only concerned about burden; by the end of the interview, she appeared to be consumed by her burdens. Georgia was the one participant that actually had an AD. She was unaware of what the AD document contained or the meaning of such a document. Georgia's AD was prepared 27 years ago along with some other "legal papers." Like other participants, Georgia felt being kept alive would be a waste of "time and money."

The researcher asked Georgia for clarification on what Georgia meant by a "waste of time and money." Georgia said,

> I want to be at peace. I want to be a peaceful time[*sic*]. I pray for a peaceful time. I've seen some and I heard of some people fighting it, and I don't want to do that. I don't, I don't know what determines that or how you avoid fighting it. I don't want to die, but if I have to die, I want it to be peaceful, and I don't want it to be prolonged. I hope the Lord takes me peaceful, that's all.

Georgia's expressed a segment of that "peace" as leaving no burdens for her family to have financial or otherwise.

Constance had heard the term Advance Directive but stated:" I really didn't understand it." Constance cares for her disabled daughter, so Constance was particularly concerned about having her affairs in order. She said:

> I wouldn't want to be hooked up to no machine. Just let me go in peace. I wouldn't want her (directing her head at Constance's daughter) to see me like that. Anyway, all that would be a waste of money and I wouldn't want to be a burden. Whatever I have, I want it to go to her (directing her head at her daughter).

Constance made a solid case for taking care of her matters of business and death. Yet, Constance has done nothing to ensure that her daughter would not have to share the financial and psychological burdens if and when Constance was to "pass" before her daughter. The researcher asked her if anything was done to safeguard her daughter against any such burdens. Constance said, after the researcher clarified what an AD was, "No, I don't have that, but I do have those papers to fill out and get that into action."

Emma said, "I have talked to my husband about how I would want to be treated if something happened to me." Her husband had a good friend that died a torturous death. Emma said that watching him die was what stimulated her to talk about "it." She said she had no idea how emotionally painful dying could be and how family members may disagree what they want for their loved one. Emma said:

> I did not realize … I told my husband if anything were to happen to me please let me die at home and don't let them treat me like Jon (Emma's husband's friend). There is no reason why Jon should have died like that.

Emma said, "I have talked to my husband about that, but I didn't fill out any legal papers or anything. I thought what we discussed was enough. I just wouldn't want my husband to have to do that." Like most of the participants who verbalized the importance of undue burden to family and loved ones, she was ill-prepared to ensure her last wishes would be taken care of according to her specifications.

Mr. Robert Lee was the "happy-go-lucky" participant. He has a sister that resided in Ft. Lauderdale. He visits with his sister on a regular basis. Mr. Robert Lee said he has not talked to his sister, nor does he plan to talk about the subject of death or disposition of his remains. His sister is the only means of social or family support for him other than some friends he "hangs out with."

Mr. Robert Lee does not spend time thinking about how things would be handled when it is "his time to go," as he puts it. Mr. Robert Lee said:

> No, no, when it's your time to go it's… That's it. I don't really care. When it's over, it's over. It doesn't matter. You won't know. You just need to be fair and live straight. I don't be worrying about it.

Mr. Robert Lee portrayed an attitude of disregard for any subject related to death or the disposition of his remains. Mr. Robert Lee was the only participant who did not express any distress over the possibility of posing a burden, financial or otherwise, to anyone; if even he were to survive his sister.

Betty was one of the youngest participants (age 66). She worked in medical records most of her working years. She appeared to the researcher to be the most intelligent of those she interviewed. Betty used correct English; she was familiar with the proper words for AD documents and medical vocabulary. She was able to verbalize, in a sophisticated manner, to the researcher, what medical resuscitation is. The researcher attributed Betty's knowledge to her years transcribing medical records through handwritten and doctor's dictations.

During the interview with Betty, she said:

> I have to help take care of my daughter and her two children, they live with me, but it is okay, I can't take it with me. I would not want any money wasted on me, especially if that money could be used for something more meaningful.

The researcher felt Betty's statements summarized the feelings of others that were also concerned about being a being a financial burden to their families. Betty stated what other participants also said about not wanting to be a burden in a short, complete, and concise manner. Her statements reflected the focus of financial affairs that were echoed by the other participants. Also, like most of the other participants, Betty said she would want to be kept comfortable if she were in a state that left her unable to speak for herself. Other than that Betty said, "Just let me go in peace."

The role of social support emerged in connection with burdens. Social support was used as an avoidance measure by the participants but did not hold enough weight by itself. Social support was interpreted as a "social support and included the responsibility of social support." The interpretation of social support will be discussed in Chapter Five.

Religiosity/Spirituality

All of the participants in this study believed in some sort of religiosity/spirituality. There was a question of religious affiliation on the demographic questionnaire that the participants filled out before the initial interview (see Appendix J, labeled" Demographic Questionnaire"). All the participants noted they were Christian on the demographic questionnaire, so the researcher received this information before any questions were asked.

When Paul said, "We just don't talk about that," referring to religion and death, his statement was a bit unsettling for the researcher. Paul began to express a deep and profound belief in God and God's role in Paul's perceptions about death and dying. The researcher did not have to ask Paul if he believed in God. The researcher asked Paul if he had anyone close to him had died in the hospital. Paul was willing to divulge information relating to his daughter and began talking about how such a situation would relate to him. This is the point that Paul became irritated but said:

> That's all I believe in. He puts you to sleep and he wakes you up. That's what I believe, I'm a believing man. He let you know each and every day you walk, he knows about it. God he knows about you. When I was born Jesus Christ was there. "I don't know it all but that's what I believe.

As previously mentioned, the interview with Paul immediately changed when the subject of death was introduced. Although Paul articulated, "we just don't talk about that," the researcher felt that it was important to Paul to communicate how God fit into his premonitions about dying.

Bobbie wanted to pray before the interview began; her prayer was an indication to the researcher the deep conviction and the influence of God in Bobbie’s life. Bobbie used words like “thank you Jesus, dear God,” etc., in our opening of the interview. The interview continued after we prayed. She did not ask, nor was Bobbie concerned, if the researcher was a Christian or had any other religious preferences.

When the researcher asked her, “Are you a religious person?” (even though the researcher was aware of Bobbie’s strong conviction by the prayer at the beginning of the interview), Bobbie said:

> Yeah, I know he’ll take care of me and I’ll be going there to be with him. That’s where I’m going to be. The Lord lets me live and determines when I will die. I don’t have to do anything but be ready, when it is my time, and I don’t want there to be nothing in my way to stop me from being ready when he comes for me. I go to church try to read my Bibles every day pray every day” [*sic*]. The researcher previously noted that Bobbie was a Christian who believed in God and Jesus Christ; therefore, the researcher deleted the question.“ Do you believe in God?”

Georgia, a lot like Bobbie, vocalized her convictions about religion. The researcher asked if she considered herself to be a religious person. She emphatically stated, “God by Jesus Christ is our Lord and Savior.” Georgia professed her religion and belief in God when she answered the researcher’s first question about her religion. She was the one of two participants that actually talked about a spirit or soul in relation to our physical bodies when we die. Georgia said, “Your body might be in a way that you can’t communicate with anybody, but your spirit is able to know what’s going on”.

Constance portrayed a soothing attitude. The researcher again ascertained she was a Christian who believed in God by the way she greeted the researcher. The researcher asked Constance, “How are you doing?” Constance replied, “I am doing well thank you, thank God.” The researcher did not need to probe further into the extent of Constance’s religious orientation by the way Constance brought the words “Jesus Christ and God” into the words during the interview.

As the interview continued, Constance was asked, “Do you consider yourself to be a religious person?” Constance responded, “Yes, oh yes, yes. Uh, I believe that when uh it is my time, when I die, it will be a resting period for when Jesus comes. If I live when he comes fine, but if he puts me, if he fits for me to sleep then I’ll just be resting until the second coming." At that point in the interview, the researcher interrupted Constance so she could clarify what was meant by “the second coming.”

Constance continued:

> Jesus, the second coming. I do not fear death, I used to, now I am at peace. I am so thankful. I am just thankful for the time, thankful for the relationships, experiences, and the glorious life he has given me. I go to church on Saturday. I am a Seventh Day Adventist.

The researcher again could feel the peace enveloping the environment as Constance spoke about her religious conviction.

The researcher was perusing the demographic data sheet with Laree. The researcher noted that the question on the demographic questionnaire (Appendix J)had not been answered. At that point the researcher asked Laree for her religious preference. Laree said;

I am a believer, a Christian person that believes that God has the first, always the first the beginning and at the end. I am a very strong believer in religion type foundation because God has more power and he said that he will always be with you from the beginning and up until the end. Neither forsakes you. So you put your trust in God and not man because he (God) is our doctor. He uh … took the strikes on his back for our because we sickness is a sin so we are here by all of his strikes, and if you believe that (God) is your doctor and that God took the strikes on his back for our healing. He said, “Trust in me, believe in me, and uh … receive your healing.”Because my faith is based on religion of whatever sickness you have you have because Satin has put illness on you. God don’t put no sickness on you because he uh … uh … taking care of you that’s why he died on the cross, that’s why he took the strikes on his back for our healing so that we could be well and made whole.

Mr. Robert Lee, the participant the researcher described as “happy go lucky,” was brief in his communication about God. Mr. Robert Lee said, “I believe in God. I don’t go to church on a regular basis, but I believe. God determines your path if you live or die” [sic].The researcher attempted to probe Mr. Robert Lee for more information on his religious beliefs but felt that the conversation about religion with Mr. Robert Lee had reached an end.

Marie, a self-proclaimed Christian woman with a strong belief in God, revealed a preoccupation about the death of her husband, three years before. The researcher felt she had opened wounds that were just starting to heal when talking to Marie. She said it was because of her faith that she was able to get through her husband’s death. Marie said:

> Oh, I can't tell you the days and nights I prayed, during Joe's illness, asking God for the strength to get through this. You know, Joseph did not want me to call anybody, but that last night when he was throwing up blood and he collapsed, there was nothing else I could do.

The researcher could feel the presence of comfort as Marie spoke of the anguish she endured during the last days of Marie's husband's life.

Betty was asked to tell the researcher about her religion. The researcher was aware Betty was a Christian by the questionnaire. Betty said:

> As far as my faith is concerned, I feel my religion has part in how I die or when I die. What I mean is ah, God is my maker and he determines when I die, I have a soul, and I hope and I pray that my soul will go to heaven.

Since the researcher kept a journal throughout the interviews, the researcher made a note that she did not ask Betty how or what role religion played in "death." The researcher concluded that Betty made the connection between God, death, and dying due to the topic of the research.

Emma is the participant that the researcher felt had a glow around her. She talks about her relationship with her God in a soothing sort of way. Emma attends church on a regular basis and involves her grandchildren in her religious ceremonies. She said:

> It is important for children to be exposed to religion. That is one of the problems with the world today. People have gotten away from the church, praying, and the meaning of faith, having faith in God, and the power of his ways.

Emma is vigorous and enthusiastic in speaking about religion. The essential element of her religion is evident in her words, her calm, soothing demeanor, her "voice."

Bobbie, the participant with 12 children, 11 still living, proudly said, "Well, I just wanted, I said, I want my daughter that you know, my closest daughters I got around me, to take care of me if I am not able to take care of my own self" [*sic*]. She continued:

> Well, if I can't do nothing [*sic*] for my own self, they can do what they think is best. I didn't worry about being put no, no nothing on my children that is not necessary for them to be on them. That's what I was thinking about, the children Well to do the best they can. If they can't do it they own self, just turn it over to the Lord and he'll know what to.

Georgia, the second eldest participant, attends a senior day care center that keeps her active three days a week. She lives with her son, daughter-in-law, and granddaughter. Georgia has an AD. Georgia spoke with a tone of worry and concern regarding matters that might have to be taken care of by her family. She said she tried to take care of everything so "they would not worry." Georgia said if anything needed to be taken care of, her son would take care of it. She said, "I don't know if he would be able to do that, his wife, my daughter-in-law would probably have to take care of things." She expressed her concern over her son's emotional grief if she were to pass away. Georgia said, "my son takes care of everything for me." She conveyed a sense of security as she told stories of how much her family takes care of her.

It was painful to see Paul get up out of the chair so we could go inside the house and conduct the interview. It was evident how debilitating his back pain had become. Paul spoke highly of his daughter he was living with. He was the participant that did not want to talk about death. Paul said, "She (pointing at his daughter sitting in the yard) would take care of dat"[*sic*]. I made sure she know [*sic*] what to do." The researcher wanted to probe the conversation with him about “what to do,” but Paul was irritated when the subject of final remains or dying was initiated by the researcher. He mentioned an ex-wife who also lived in Ft. Lauderdale. Paul spoke of her in a casual sort of way as if they were friends with each other. He did not elaborate on the relationship with his ex-wife other than to say, “We good friends now; I guess I just ran around too much when I was younger.”

Mr. Robert Lee, the “happy-go-lucky” participant that had a sister in Ft. Lauderdale, visits his sister at least once a week. Mr. Robert Lee said, “I go over and sit with her; she’s the one I have listed on everything if something were to happen to me.” Mr. Robert Lee said, “When it’s over it’s over. It doesn’t matter. You won’t know.” He spoke of his friends, with whom he spends a lot of time with. Mr. Robert Lee’s friends seemed to be a very important factor in social life, and his friends provided what little enjoyment he had in life, socializing with them. Mr. Robert Lee said, “I sit around with my friends just shooting the bull and drinking beer and playing cards.”

Constance was very concerned she would leave her disabled daughter to care for herself if she were to die today. The researcher did not think that Constance has made the necessary arrangements to help protect her assets necessary to provide Constance’s daughter with adequate financial means. Constance was the participant that “had those papers, but never filled them out.” She has a brother who lives with her. She said other than her brother, her church members offer her the “comfort” she needs. Constance is ill-prepared for matters in her life and death, but the researcher felt it was best not to interfere with whatever preparations were made or not made for in the event of Constance’s demise. Constance did request “those papers” (AD documents) from the researcher. The researcher did return AD forms, web addresses, and references for Constance to peruse if Constance wanted to complete them on her own or with help from her support group. The researcher did not feel it would be ethical to offer any more aid to the participant at that point since the participant had already stated: “I have those papers over there; I just never filled them out.”

Emma is married living with her husband and her children in close proximity. She said; “Me and my husband know what we want if something were to happen to us. I have not spoken to my children because I haven’t felt the need to do that; besides, my husband knows what I would want.” The researcher asked Emma, “Suppose you were not around?” Emma said, “My children are well-educated (all three had college degrees); she continued, “It’s not necessary to come out and tell them. They would know what is best.”

Betty was divorced and worked in medical records most of her adult life. Betty said, “If anything were to happen to me, my children would make sure everything would be taken care of.” The researcher asked Betty what she meant by “everything taken care of?” Betty said, “to make sure I was comfortable.” She has a son and a daughter so the researcher was curious to know if Betty felt confident that both children would be in agreement about what care Betty would receive.

The researcher asked Betty if she had talked to her children about what she may want if she were unable to speak for herself. Betty replied, “I’m in good health; I have plenty of time for that.” Betty spoke in a well-determined, confident, and proud tone that she felt her children would do what was necessary for her if she were incapacitated.

Laree lives with her 34-year-old daughter. Laree told the researcher that her daughter wants to move out and live on her own. This presents a financial problem for her. She depends on her daughter financially. Laree said, “She’s grown (Laree’s daughter); she said she wants her own place; it is time.” Laree was saddened as she spoke those words, and it was more than the financial aspect that the researcher detected. As the researcher and Laree ended the topic, of the daughter moving out, Laree said; “I don’t know what I’m gonna [*sic*] do.”

Laree also mentioned other brothers and sisters in close proximity in Ft. Lauderdale. She is very active in her church and spends time volunteering in the church since her retirement. It was evident to the researcher that her daughter is a pillar of emotional support in her life, by the tone and mood of the interview and involvement of Laree’s daughter name in the conversation during the interview.

Marie attends a dialysis treatment center three times a week. She was forced to watch helplessly watch her husband died. Marie does not have a strong support system. Marie does have a nephew who “looks in on her,” but the researcher did not feel their relationship was more of a responsibility on the nephew’s part. Marie did say, “I speak to my in-laws every now and again, but I don’t see them often.” She was enthused to participate in the study.

The researcher thought Marie enjoyed the researcher’s company more than the interview itself. She was not able to “get out” very often. Marie’s co-morbidities associated with her diabetes haves affected her sight and mobility. Most of the interview conducted with Marie consisted of her talking about her husband. It was evident to the researcher how desperately Marie felt isolated and alone without him. In speaking with Marie, the researcher could feel her isolation. The researcher did suggest to Marie that she contact one of the senior day care centers to see if that would help Marie with some form of socialization. Marie said due to the fact she spends so much time at dialysis, it is hard to be involved in anything else.

Fatalism. Words mentioned by the researcher during the interviews that suggested death or vegetative states (explained to the participants in layman terms) such as “care planned for you near the end of life, living will, ADs, or any implication about advanced end-of-life care planning, seemed to provoke an uneasiness in some of the participants." However, other participants were firm and self-confident in their communication about “when the time comes.” There was one participant, Laree, who did not convey a fatalistic view. Therefore, Laree, Betty, and Emma described beliefs that were more realistic and religious, representing acceptance rather than a fatalistic view.

Laree, the participant still living with her 34-year-old daughter, spoke of her realistic beliefs in terms of the care she might need at the end-of-life and not able to receive it. She was at the complete opposite ends of her beliefs. Laree verbalized, “There is always hope, some new treatment or something that can be done.” She felt that due to her financial status, she would not receive the care that may prolong or save her life. Laree exhibits both a realistic view of the care she may need and what is financially accessible to her. She said; “Some hospital people turned you down [*sic*] but I think that now the President has passed that law for that [*sic*] not only for senior citizens, but for anyone that needs to go for medical treatment.” Laree continued and said:

> Because of the insurance, or because you don't have a lot of money, or because you know you know, a lot of people cannot afford medical insurance and they know if they go that they won’t get the right treatment or right medical treatment

> that they need. When I wanted uh…came into my mind saying that uh[*sic*]. I don't know if whether it's true or whatever but there the way some people are saying that if I have to suppose that you have to go to the uh… nursinary [*sic*] home (researcher's interpretation is Nursing Home). Is there's a shortage lot of insurance don't cover Nursing Homes and will they get the right kind of treatment, or will they just send you home?

Betty said~~;~~ "I'm in good health right now and um that's something my … uh I have plenty of time to think about." Betty holds the belief and says that, "I know one day we have to go. It is a part of life to have it's just something that is going to happen." When the researcher asked Betty what she thought would happen to her if she was unable to speak for herself in a vegetative state or death was imminent, Betty said, "I hope and I pray that my soul will go to heaven." This statement reflected sentiments shared by other participants. The researcher did not perceive Betty's opinion as a fatalistic but rather a trust in God as a source of peace, comfort, and hope. Betty said; "God would do what he feels is best for me." The researcher interpreted that "hope" as a sense of "God" doing what he thought was best for Betty. The researcher interpreted this depiction as a sense of optimism, courage, and faith.

Emma's beliefs appeared to the researcher to be very similar to Betty's. The researcher interpreted their perceptions as almost the same. For example, Emma said she understood that we will all die someday. She said, "I will turn it over to the Lord my time comes." Emma was more interested in how she would not want to die as opposed to the aspects of fatalism in relation to her death. Emma experienced her husband's friend who died a tortuous death while in the hospital. The experience was still a fresh wound in Emma's mind.

The researcher perceived that the experience was emotionally devastating, leaving concerns for Emma in relation to death and suffering. She said that she had no idea how emotionally painful dying could be and how she witnessed the friends family members disagreeing what they wanted for their loved one. Emma said:

> I did not realize … I told my husband if anything were to happen to me please let me die at home in comfort and don't let them treat me like Jon (Emma's husband's friend). There is no reason why Jon should have died like that.

Paul, the participant with chronic back pain that debilitated his physical activities, showed irritation by the tone of his voice when the researcher asked him, "Have you talked to anyone about what you would want done if you were not able to speak for yourself, or you were close to death?" Paul abruptly answered:

> I don't talk about dat [*sic*]; I just don't talk about that. I am not supposed to talk about that. No in my heart I don't bring it up. Nobody know [*sic*] when death is goin'[*sic* to be, but he know [*sic*]. That's all I believe in he puts you to sleep and he wakes you up. That's what I believe; I'm a believing man. He let you know each and every day you walk, he knows about it. God he knows about you. When I was born, Jesus Christ was there. I don't know it all, but that's what I believe.

The researcher's interpretation of Paul's fatalistic perception was that Paul had no control over his destiny other that it was God's choice to decide and no intervention would alter that decision.

Mr. Robert Lee was the “happy-go-lucky” participant who appeared to be living his life day by day. He had a sister in Ft. Lauderdale, and she was the closest person in Mr. Robert Lee’s life. The researcher asked; “you said your sister is the closest person to you? Have you ever talked to her about what she should do if something happened to you?” He said, “I don’t really care. When it’s over it’s over. When it’s your time to go it, that’s it. It doesn’t matter. You won’t know. You just need to be fair and live straight. I don’t be [*sic*] worrying about it.”

The previous statement by Mr. Robert Lee is comparative to the statements made by the other male participant Paul. Neither participant felt there would be any need for anything because it would be “your time to go.”

Constance lives with her disabled adult daughter. She displayed her beliefs of her final days on earth as she said; " she was trying to put her affairs in order so her disabled daughter will be properly taken care of.” Constance has been in poor health for the past three years. The inflection in her voice was somber, and she appeared depressed. She spoke as if she were on death’s doorstep. The researcher noted the sighs in Constance’s conversation. She would drop her head wringing her hand and tears welling up in her eyes. Her entire facial changed to a somber, dismal appearance (see figure 10).

Religious Participation

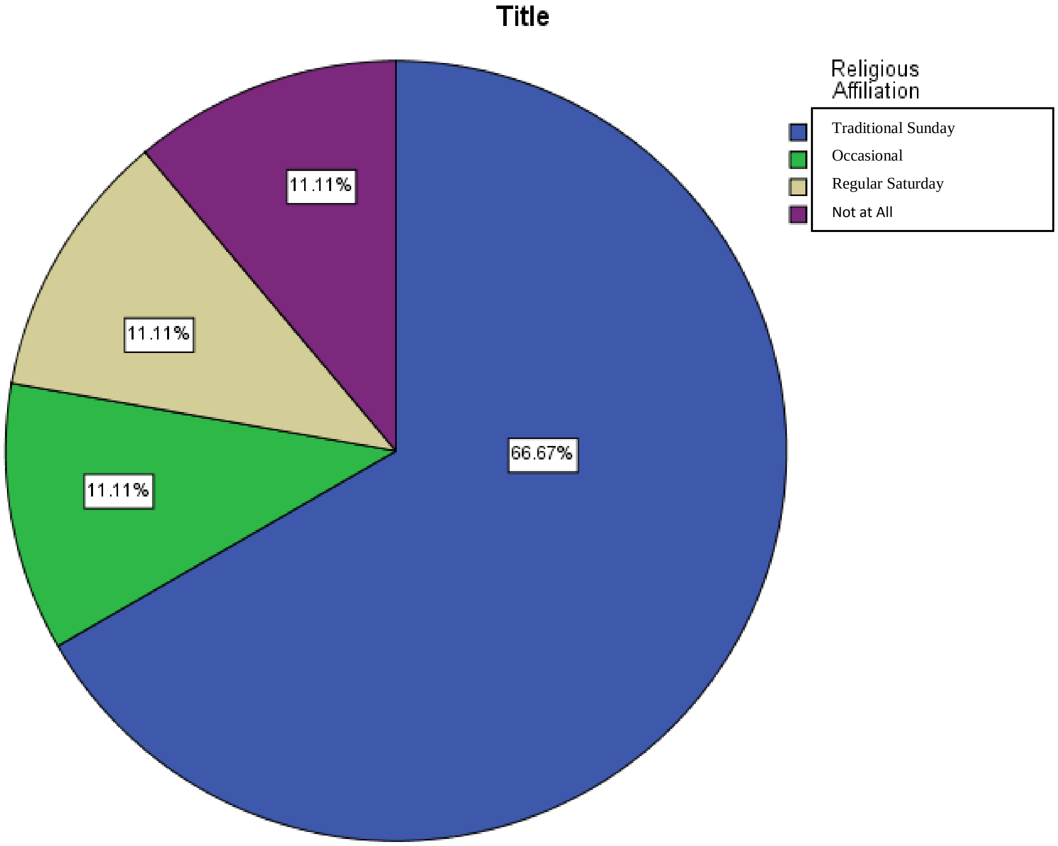


Figure 10.The participants' religious affiliation/practices.

Pain/Discomfort. The participants that stated they did not want to be in pain or to be uncomfortable when they died. They also expressed their concerns about how their family may perceive that they were in pain. The thought of death provokes a person to associate notions related to the experience of dying. Pain is a concept and is usually perceived as a symptom of distress on many levels (Tilden et al., 2004). It cannot be assumed that pain is the worst part of the dying process, but it is closely associated with the process of dying by many researchers study results (Finucane, 2002).

The participants expressed the need for comfort in relation to their families (social support), their religion (religion and spirituality), and their need for comfort was assured and they would not suffer agonizing discomfort during their dying process. The participants expressed the need for varying perceptions of physical, emotional, financial, and psychological comfort in statements made to the researcher.

Bobbie, the nurse’s aide, spoke of her wishes to be pain free, at peace, ready for the Lord, and financially prepared for death when it came. Bobbie expressed to be without pain like “when you go to sleep. Like when you just go to bed and die in your sleep.” Bobbie said, “I just don’t want to suffer. I wouldn’t want my childrens [*sic*] to see me like that or they’s [*sic*] think I was in pain if I couldn’t talk to them.” She said:

> I saw my husband die. Even though he was not sick a long time before he passed, I could see he was in a lot of pain. The doctors said he was going to die and there was nothing they could do for him, but they never said anything about doing somin [*sic*] for his pain. He passed before I started workin [*sic*] as a nurse’s aide so I didn’t know nothing bout [*sic*] that.

Bobbie added: “That was a bad, bad time.”

During the course of the interview with Georgia, the subject of death developed when speaking about ADs. Georgia was the one participant that had an AD. Georgia was asked if she could remember what types of thing might be on her AD. Georgia, without hesitation said:

> To make sure that you're not in pain. Something that would keep you from pain that would keep your mind lucid that you would know people. Uh, I think that's important. Make you feel better something to make your mind comfortable. Not only for me but so my family would know I was okay.

Georgia shared the same sentiments as Bobbie. Not only were the participants concerned about their pain, they were also concerned of how their family members perceived their pain.

Constance, the participant that worked in the doctors' dining room in a hospital, again mentioned the desire not to be in any pain. As concern for her daughter's comfort Constance said:

> Well, I wouldn't want to be hooked up to respirators. I don't want to be hooked up. Whatever I have I want it to go to her (participant directed her head toward her daughter). I don't want that she would have to look at me or anything. That would be a waste of money. Oh, I don't want to be in pain. I feel that all that "stuff" would be unnecessary, and you would be a burden to my family. I leave my fate to the good Lord. Yes that is right! (Emphatically)

Marie's husband died an agonizing death while she watched helplessly as her husband's life sifted through time and left Marie memories of an anguished death filled with pain. The researcher felt the interview was therapeutic for Marie. She was tormented over telling the torturous story of how her husband died. The researcher could see it in Marie’s eyes; she could feel it in her words. Marie did not have a close-knit family or anyone to whom she could or would vent her feelings.

The researcher felt this was the first time Marie told her side of the story. The researcher could not get much information from Marie about the things that would be important for the doctors to do or not do to her in the event she had a catastrophic event that left her incapacitated or in a vegetative state other than the blank direct statement from Marie that, “I just don’t want to be in pain when I die.” She was still recovering from the events surrounding her husband’s death over three years ago. The researcher felt obligated to listen to her. It was obvious Marie was consumed with events that continually stay vivid in her mind regarding Joe’s death.

Laree, the participant that had an elementary education, was the participant with unwavering hope. The researcher asked her about inevitable death or being in a persistent vegetative state, in terms that Laree could understand. Laree would always answer with statements like “if the doctors say that ain’t notin [*sic*] that can be done for you, you just go and find another doctor. There’s always something that can be done.”The researcher attempted to redirect questions to Laree on the same subject, but Laree’s answers were the same.

The researcher asked Laree her feelings about death. Laree answered:

> That’s a shaky thing. When I say a “shaky” thing is that, don’t nobody wants [*sic*] to talk about. Doesn’t anybody want to die, but we all have to go one day and it is a little scary thing when you talk about death you know, to me it is you know. Her posturing and non-verbal behavior changed. The researcher felt

> Laree’s demeanor suggested this subject was too distressing her. The researcher redirected the interview toward a different subject at that time.

The researcher asked Betty, “What are your feelings about end-of-life care?” Betty replied: “I would want to be comfortable, not in any pain.”The researcher asked Betty to elaborate, could you explain what you mean by “comfort without pain?” Betty said; “To go out without hurting or moaning giving for someone to come in and see me in that type of position is … um as in such pain that would hurt my family.” The researcher then asked; “Ok, when you say family, you think your family would be hurt if they saw you in that type of condition?” Betty repeated the feelings of the other participants that were concerned about the distress seeing them in pain would produce. The participants showed concern about the family’s perception if their pain.

Emma, the participant married and enjoying a retired lifestyle, said, “I have talked to my husband about how I would want to be treated if something happened to me. Her husband had a good friend that died a torturous death. Emma said that watching him die was what stimulated her to talk about “it.” She said she had no idea how emotionally painful dying could be and how family members may disagree what they want for their loved one. Emma said:

> I did not realize … I told my husband if anything were to happen to me please let me die at home. I don’t want to be in pain and don’t let them treat me like Jon (Emma’s husband’s friend). There is no reason why Jon should have died like that.

Emma said, “I have talked to my husband about that, but I didn’t fill out any legal papers or anything. I thought what we discussed was enough. I just wouldn’t want my husband to have to do that." Like most of the participants who verbalized the importance of undue burden to family and loved ones, Emma was ill-prepared to ensure her last wishes would be taken care of according to her specifications.

When Mr. Robert Lee, the "happy-go-lucky" participant was asked about death, the researcher reintegrated for verification what Mr. Robert Lee responded. "What you are saying is that you don't care that it is over, you just don't want to suffer getting there, is that correct?" Mr. Robert Lee said: "Yes, I'm sure nobody wants suffering, pain." The researcher noted Mr. Robert Lee was becoming agitated when the discussion about death was raised and felt it was time to end the interview. Like other participants, the subject of death elicited anxiety and discomfort for some of the participants.

Paul was the participant that said "that's something we just don't talk about." Paul's spoken words were eerie, almost taboo in feeling. Paul offered no elaboration on his feelings of pain/discomfort in relation to death and dying. However, due to Paul's actions, while discussing death matters, the researcher felt as if Paul was becoming irritated or anxious. He added a wealth of information to support that discussion about death was obviously anxiety producing (Vig, Davenport, & Pearlman, 2002).

All the participants were self-proclaimed Christians. The figure above depicts the regularity of religious worship at churches

Avoidance

Avoidance was the reason that Constance has not taken care of the things she needs to. However, by contrast, Constance spoke about how her time is limited on this earth. Constance depicted the dichotomies of conflicts much like the other participants.

When asked by the researcher; do you go to church on Sunday? Constance said; "I go on Saturday; I am a Seventh Day Adventist."

Constance continued:

> I feel I am associated with the Seventh Day Adventists to learn more, to learn more giving me a chance for better understanding. God has given me time to do this. This I can say, if this had happened to me three years ago, these three surgeries on one leg, I don't know. I've gotten closer to the Lord, I've understood, I found out he does not put more on you that you can bare, and I'm just thankful.

Constance then talked about her past work experiences.

> I worked in the hospital over 30 years. I've seen people have gone in the hospital and never come out. I'm just thankful; I've been in the hospital four times in the past three years and I'm just thankful I am truly thankful.

Constance's fatalism was reflected in her conversation. For example, Constance would say "a time to understand." She spoke as if she was living on borrowed time that is awarded to her to better understand her "relationship" with her God.

Georgia, the retired schoolteacher, was the only participant with an AD. She was more realistic then fatalistic in communicating her last wishes. She was not concerned with heroic treatments or anything to extend her life. When asked by the researcher what things she had on her ADs, she said, "I would not want to be placed on a machine that would be a waste of money and time and I want to be comfortable." From that perspective, the researcher interpreted her comments as realistic.

Bobbie was the nurse's aide and the participant that wanted to pray before the interview. She had idealistic views buried in her deeply embedded religious beliefs. When the researcher asked Bobbie, "Is there anything particular about when it comes to be 'your time' that you would want or not want to be done/not done if you were gravely ill; or had a stroke or something like that, that would leave her unable to communicate with anyone?" Bobbie without hesitation said, "I'm just gonna [*sic*] turn it over to the Lord."

Bobbie seemed exuberant and excited when talking about "her time," unlike other participants that became anxious and apprehensive. Bobbie said:

> I want to be with the Lord when I leave here, so I'm not worried or anything like that; if this is the way that it is, I'm not going to change anything. I would just tell them to forget it, and just hand it over to the hands of the Lord.

Bobbie said; "I'm 89, I have aches and pains, but at least the Lord saw it fit for me to wake up."Bobbie showed her gratitude of her Lord by the way she expressed her posture, holding her hands up and eyes gazed toward the ceiling saying "thank you Jesus, thank you God."The researcher perceived Bobbie's belief with no insinuations or suggestions to fatalism. Bobbie was accepting almost as if she was waiting to die and accepting death as God's will.

Marie, the participant suffering from multiple co-morbid diseases associated with diabetes and renal failure, was forced to watch her husband die an undignified, agonizing death because of his fatalistic/other beliefs. Marie knew her illnesses were going to become more severe and eventually kill her as she said, "I'll keep doin [*sic*] what I'm doin [*sic*] until the time comes, and when it does I'll turn it over to the Lord."

Marie was not willing to take the extra step and investigate other possible treatments, especially to seek more treatment for her kidney disease. Other treatments such as transplantation she did not consider due to her beliefs and strong religious convictions. Marie said:

> I go to the dialysis treatment center three times a week. I've seen other patients that have tried other treatments. You know anytime they (other patients) tell me they are goin [*sic*] to have surgery or this or that, I never see them again .

Marie added, "I know I can't go on forever like this. Seems like every time I see my doctor he finds something else wrong with me."

The researcher encouraged participants to express their perceptions about when it was the participant's "time to go." The researcher wanted to understand the participants' perceptions about matters of end-of-life care, expressed in the use of AD documents. Research has supported the use of ADs as one tool used to improve medical outcomes in the African-American community (Poem & Finnie, 2010; Franklin, Schlundt, & Wallston, 2008).

Understanding the perceptions of elderly Black Americans and pre-planned end-of-life care for this underserved group of people. As stated previously, fatalism is closely reported and associated with medically underserved populations and persons with cultural beliefs that are different from those persons who devised the concept of ADs (Freeman, 1989).

Chapter Summary

In summary, 12 interviews were conducted in an exploratory descriptive manner (Creswell, 2002). Data were analyzed from nine interviews that were conducted with elderly Black Americans who ranged in age from 66 to 88. The interviews with seven females and two males were transcribed and analyzed by the researcher. Information was obtained during eight 60-minute interviews and one 30-minute interview.

The analysis of data led the researcher to describe the emergence of four themes: educational deficit, financial/other burdens, religiosity/spirituality, which all culminated into what the researcher interpreted as a dominant over-riding theme of avoidance. The exploration and meaning of the study and the themes that emerged are discussed further in Chapter Five.

The researcher was perplexed as she interpreted the elderly Black American participants' perceptions about ADs. The participants expressed contradictions in what they were portraying to the researcher, paradoxical plans for their end-of-life care, and ambiguities about when they would take care of "things."

Although perplexing, the information that participants shared with the researcher aided the researcher to have a better understanding of perceptions of elderly Black Americans about ADs. The researcher expects that new knowledge obtained from the perceptions of older Black Americans may assist healthcare providers to improve the quality of end-of-life care, expressed in AD documents, for this vulnerable population.

CHAPTER FIVE

Discussion and Conclusion of the Inquiry

Exploration of the Meaning of the Study

Black Americans are less likely to know about or to complete ADs despite the availability of such preplanned end-of-life care documents (Born et al., 2007: Caralis et al., 1993; Eleazer et al.; Kiely et al., 2001). The purpose of this qualitative study was to explore elderly Black Americans' perceptions about ADs. During the interview phase of the research, participants elaborated on what types of procedures they may or may not want if they were rendered in a persistent vegetative state or incapacitated (presented to the participants' intellectual level of understanding). Participants perceived the idea of advance planning as unnecessary. The participants' perceptions are expressed by the interpretation of the researcher in the discussion to follow.

Congress passed the PSDA Congress sought to reimburse physicians through Medicare and Medicaid, as incentives for them to advocate ADs for their patients. ADs have been identified as a measure that can decrease disparities among the vulnerable elderly Black American population (U.S. Department of Health, *Healthy People 2010: Healthy People 2000*). The researcher agrees with the purpose of ADs. The researcher has witnessed deaths of elderly Black Americans that have been much less than dignified due to a myriad of reasons. One of the most prominent reasons for the needless suffering of patients' families, nurses, and physicians and, most of all, the patient, was that there was no AD in place.

As the researcher contemplated the findings of this study, she received communication that one of her participants, Bobbie, had "taken ill," during the writing of this document. Bobbie's condition was serious; she was in the hospital. Bobbie was the oldest participant and worked in a hospital for 35 years as a nurse's aide. She did not know what ADs were.

Unfortunately, the situation with Bobbie is exactly why there was a need for Bobbie to have an AD. One of her daughters informed the researcher of Bobbie's condition when Bobbie became ill. The daughter was not the oldest but was responsible for "keeping check" on Bobbie. The researcher recalls the interview with Bobbie. The researcher asked, "Is there any of your children that would know what you want?"Bobbie expressed to the researcher very clearly what she would want/not want if she were not able to speak for herself in a medical situation. As the researcher reminisced about that interview and the environment, the researcher recalled Bobbie said, "The one that stays in this house, this house. My house crosses [*sic*] the street. Maundy-Ann and any of the rest of them (referring to her children). The rest of them live further out, they knowed [*sic*] what to do."

Bobbie continued, "When the Lord is ready for me, I am ready to go. I don't want to be hooked up to no machines or anything like that, it costs too much money. I don't want my daughters to worry about taking care of me. I know my daughters will know how to take care of everything, you know finnanical [*sic*] and everything." Bobbie said that she never had that conversation with any of her children. So, the researcher wondered if Bobbie's individual wishes and her children's wishes and/or Bobbie's wishes and her children's decisions might be in conflict with one another.

Bobbie's situation illustrates how very little has changed today in reference to initiation of ADs in the Black American community. As previously stated, Black

Americans are less likely to know about or to complete ADs despite the availability of such preplanned end-of-life care documents (Born et al, 2007: Caralis et al.; Eleazer et al., 1996; Kiely et al., 2001). Researchers have validated that Black Americans do not plan for end-of-life care. A major reason for their lack of planning is the limited knowledge and access to information about end-of-life care and preplanned care/ADs (Welch et al., 2005).

Meaning

The transcripts produced from the interviews became the primary source of data (Miles & Huberman, 1984, 1994, 1994a, 1994b; Rubin& Rubin, 2005;;van Manen, 1990). Thus, the transcripts produced from the interviews became the primary source of data (van Manen, 1991). The inquiry of the exploration of the perceptions of elderly Black Americans about ADs was seen and interpreted through the researcher's lens. By utilizing van Manen's approach, the researcher also attempted to view the participants' perceptions about ADs from their viewpoint.

The participants portrayed little or no interest in AD documents after they received knowledge about them. The researcher presented information to the participants in lay terms that the researcher felt appropriate for each of the participant's educational level. The exploration into the perceptions of elderly Black Americans about ADs was to gain insight into present, preplanned, end-of-life care with the expectation that results might help improve the quality of life at the end of life for elderly Black Americans.

The researcher gained valuable information by being invited into the participants' home environment for all interviews. The participants' answeres about their perceptions about end-of-life issues evoked nuances regarding their lack of information about ADs.

Since the researcher was the of same race and ethnicity as the participants, the researcher felt she was more likely to be accepted as an insider (or was coming to the interview from an emic perspective) (Leininger, 1991, 2002). Therefore, the researcher as a Black American was more likely to be privy to information than “others” (or outsiders who would view the situation from an etic perspective) (Bonner & Tolhurst, 2002).

The ethnographic component of this study was interviewing all participants in their homes. Interviewing in participants’ homes added an important element to the data. Malinowski, Luckhorn, and Mead are the forefathers of ethnographic research (Creswell, 2005). Donovan (2006) describes the essence of ethnographic data and the enrichment that field notes about the environment add to the richness of the data: “…. as the ethnographer develops ideas these are tested against observations and vice versa. There is a back and forth process of data collection and analysis, involving switching from emic to etic perceptions and testing them against each other” (p. 173).

Although this was not an ethnographic study, the information noted in field notes regarding the participants’ environment added trustworthiness to this exploratory study (Sake, 2005; Yin, 2003). The individuals in this study lived in the same community and shared values, beliefs, norms, and life ways (Leininger 1991; 2002). Leininger identified concepts associated with religion, ethnicity, and race as part of a person’s environment. Personal ethnic and religious identities refer respectively to the identification by self of one’s ethnic background.

The interpretations of themes were generated from the data provided by the nine participants. The researcher continually searched the meaning of the social phenomena through her lens and through the lens of the participant. The continual searching by the researcher enhanced the development, understanding, and clarification of the themes as they emerged.

The Interpretive Analysis

The researcher's curiosity about why she had encountered so many elderly Black Americans who had not signed Advance Directives provided the impetus for the qualitative approach. The data analysis approach suggested by van Manen (1991) supported the rationale for rigor and the interpretation of the results. van Manen's method is recommended by other qualitative researchers for topics that require a detailed exploration such as the perceptions of elderly Black Americans about ADs. Other commonalities among qualitative researchers are the use of thematic analysis during the interpretive phase of the study (Creswell, 1998, 2003, 2005; Miles & Huberman, 1994; Munhall, 2007; Speziale, & Carpenter, 2003, 2007; van Manen, 1990, 2002).

By using the one-on-one interviews, the researcher was able to guide the participants and focus her interpretations on the phenomena of their perceptions about ADs. The participants were able to reflect on the reality of their world in which they live and articulate their perceptions about ADs. The themes emerged and were interpreted by the researcher. The themes: educational deficit, burdens (financial/other), religiosity/spirituality, and culminating into a dominant, overriding theme of avoidance. The researcher identified sub-themes of trust/distrust, responsibility and social support, fatalism, and pain/discomfort. The sub-themes were mentioned in the research literature and was interpreted to be present by the researcher. The participants did not make mention the sub-themes specifically.

The Significance of the Question

When the participants were initially asked: Can you tell me what an Advance Directive is?, the participants (seven out of nine) did not know about ADs. Bobbie said: “What was that honey advance, advances [*sic*]?” However, two participants, Betty and Constance, did have knowledge. Betty said; “Okay, an Advance Directive is when, ah, you go to the hospital and you don’t want anyone to resuscitate you.” For elaboration, the researcher asked Betty to explain what she meant by “resuscitate?” Betty replied: “Say for instance you were just, uh, just don’t want anybody to give you anything to prolong your life.” Therefore, Bobbie was an example of the uninformed, and Betty was informed.

Constance’s interpretation of an AD was: “An Advance Directive is something that if something was to happen to me and I can’t give the permission or whatever for the care, I have someone to umm … that has the authority to do that.”Laree said:“Ah, the certain kind of care that I would like to have if I am unable to speak for myself.” The researcher did not gauge Laree’s explanation as a definition of an AD. Laree said: “I would expect my daughter to take of everything.”

Georgia said she had an AD, but she had not read what was in it. Emma admitted with no hesitation that she was unaware of ADs or anything associated with them. Mr. Robert Lee and Paul had no idea about ADs.

Participants were most eager to articulate their life stories without prompting from the researcher. Participants appeared to avoid speaking about ADs. The researcher had to bring them back to the topic. The researcher used the beginning of the interview to warm up both the participant and the researcher. The researcher felt the questions centering on the perceptions about ADs were being avoided. The reactions of the participants to the researcher's questions became the evidence that there was much confusion among the participants about the concept of ADs.

Participants were unaware of the implications of having or not having an AD. The researcher could recollect the emotional response when the participants were asked the question, "Have you had a relative or close person to you die in the hospital?" Participants responded, "Yes." Surprisingly, the researcher did not have to probe the participants for them to continue with their elaboration on the subject and stories of relatives or significant others dying. Yet, when the researcher followed with the question: "Did they (significant other) have an AD?," all of the participants changed their attitude to one of avoidance, and perhaps, anger or resentment. The participants became somber, but again, avoided the researcher's question and did not address the issue of ADs. Instead, they continued their narratives about their experiences with the death of a significant other or relative.

The interpretation by the researcher was that the participants' significant others who died in the hospital did not have ADs, determined by the way those significant others' explained how the lives of those people ended. When the researcher explained what an AD was to the participants and asked the participants if they had ever been introduced to ADs (papers, forms, AD documents at their primary doctor's office or hospital), all of the participants reported no. The researcher interpreted that Mr. Robert Lee and Paul would have answered no because they had no knowledge about such papers.

Georgia, the one participant who did have an AD, was forced to change her primary care physician due to a change in her Medicare insurance. At the time of that change, ADs were introduced to Georgia. Later, after data collection, the researcher went to visit the participant (the researcher lives across the street from the participant). The participant showed the researcher a packet of papers given to her on her first visit to her new primary care doctor and asked the researcher for an interpretation of these papers. The researcher explained what her AD documents meant to Georgia.

Distrust in the health community for Blacks continues to plague the Black population seeking preventative healthcare. Preplanned end-of-life care and the use of ADs are considered preventative care. Musa et al. (2009) conducted research of distrust of the medical system by Blacks. Their results concluded that there was less distrust among the older Black population.

The distrust finding was a discovery noted in prior research on this study topic. The researchers changed their methodology by separating known obstacle factors attributed to earlier research. Musa et al. (2009) recognized that trust in an individual physician was totally different than trust in doctors. The individual relationship was not identified distrust as a factor that was not determined as a single entity compared to prior research on the problem of distrust. The researchers’ results from this study revealed that elderly Blacks spent more time with their physicians than the younger generation of Blacks. The results from this study could significantly increase the trust in the elderly Black population if individual doctors who spent time with their elderly Black American patients could introduce a program to educate elderly Black Americans about ADs. Measures to increase trust could increase the trust issue as a tool for the initiation of ADs research (Allen, Hilgeman, Allen, 2011; Byrdet al., 2011; Durant, Legedza, Marcantonio, Freeman, & Landon, 2011; Hanet al., 2011; Scharff, Mathews, Jackson, Hoffsuemmer, Martin, & Edwards, 2010).

Slavery, use of Blacks for medical research, and sanctioning of discriminating laws by the government were all reason for Blacks to distrust all types of bureaucracy. During the late 40s and early 50s, employment opportunities in the north were available to Blacks. Blacks could hold civil service jobs, accrue a pension, have health insurance, and, most importantly, have equal educational opportunities for their children. Many southern Blacks relocated their families to the north. It is bewildering for the researcher to remember that during her lifetime, Blacks were not allowed to vote. Below is an example of one of discrimination of Blacks as follows (see Figures 8 and 9).

Plessy v. Ferguson (1896) was a landmark U.S. Supreme Court ruling in the jurisprudence. The law required segregation of Blacks in public facilities under a “separate but equal” policy. The Supreme Court doctrine paved the way for indoctrination of The Jim Crow Laws, 1876 and 1965 (U.S. Supreme Court Plessy v. Ferguson, 1985).

Southern legislators composed laws of segregation called The Jim Crow Laws. The laws the lives of southern African Americans, identified as “colored.” The laws were enacted to control Black Americans through economic, and political segregation to promote White supremacy, in southern America. Black men and women were labeled as physically identifiable and subordinate human beings. The Jim Crow Laws segregated Black Americans from public parks, restrooms, all public accommodations, libraries, and swimming pools (Fireside, 2004).

Figure 10. Segregation sign at public drinking fountain, Jim Crow Laws.

Figure 11.Segregation of services in response to Jim Crow Laws

The concept of preplanned end-of-life care/ADs is something that is not usual or customary in the Black American community. The Black American community is rich with cultural values, traditions, and beliefs that are largely influenced by religious and spiritual beliefs and practices. Participants' comments about ADs or their avoidance of the topic confirmed the influences of the Black American culture and ingrained traditions.

The Black American Population

This study uncovered knowledge about how elderly Black Americans perceived ADs. The overriding theme of avoidance was interpreted by the researcher to permeate all the other three themes. The three major themes of educational deficit, burdens financial/other, and religiosity/spirituality underscored the vulnerability of elder Black Americans when they are faced with a terminal illness. The fourth overriding theme was interpreted by the researcher that avoidance permeated the other three themes. A nurses' responsibility to promote quality of life at the end of life will continue to be compromised if elder Black Americans do not discuss end-of-life-care issues with their loved ones and their healthcare providers.

The use of interpretive analysis through an exploratory descriptive methodology allowed the researcher to utilize data to transform the voices of the participants into themes to aid in the progression of knowledge that may be used as tools. Establishing community outreach programs, increasing available literature, establishing trust in healthcare members, and engaging patients in culturally appropriate end-of-life concerns with patients are fixes that would only require active participation. Constructing interventions through interpretations from the participants could attain a goal to improve the quality of death for the underserved elderly Black American population. In keeping with active participation of culturally appropriate dialogue about ADs/preplanned end-of-life dialogue, the researcher hoped that the results of this study could be transferrable across all Black American populations (Creswell, 2003).

The voices of the participants provided the foundation for knowledge that may aid to decrease health disparities and improve the quality of life for the elderly Black American. Unfortunately, because of the history of Black Americans that include a trail of mistrust, some Black Americans may fear the medical community. Even if they have knowledge about ADs, they may refuse to sign AD documents. Incidents past and present, real or imagined, and spawned out of conspiracy theories continue to affect trust of the medical community (Thomas & Quinn, 1988). Nursing education is needed in order for nurses to truly acquire cultural competence. In order for nurses to truly acquire cultural competence, knowledge of other cultures and an attitude of humility and respect may pave the way to build trust (Campinah-Barcote, 2009). The research by Shrank et al. (2005) and Campinah-Barcote reinforced the need for cultural sensitivity and adjustment in nurses' expectations of what patients think and feel. Hopefully, in the future, all nurses will have the communication skills and cultural knowledge to appropriately address patients' and patients' families' end-of-life choices.

Cultural competence may increase nurses' humility (Campinah-Barcote, 2009). Humility will help build a foundation of trust so that nurses of all cultural backgrounds will be privy to their patients' concerns. Divergent practices in nursing education are needed to refocus on patients' families' culture and social structures when addressing end-of-life information. The availability of futile treatments in the face of catastrophic medical situations should be an expected topic of discussion. Perhaps nursing students in a community course could be paired with families from different cultures in order to promote in-depth knowledge of different cultures.

A lack of education has been noted to prevent any constructive change to occur in an individual. If education is the key, then education must initiate communication between individuals who have the resources and knowledge to make logical decisions. If nurses have acquired the education to promote change, nurses may help the less empowered to make informed educated decisions about their end-of-life care (Porr, Drummond, & Richter, 2006). Measures as reported by Musa et al. (2009) concluded that trust issues in the Black American community should be addressed. If the health professional discusses end-of-life care concerns and imparts AD knowledge to Black Americans, ADs can become a tool to increase trust of Black Americans (Allen et al., 2011; Byrd et al., 2011; Durant et al., 2011; Hanet al., 2011; Scharff et al., 2010).

The Interpretation of the Themes

Educational Deficit

The power of education and the lack of education were recognized during the time of slavery and continue to be a powerful influence today to the detriment of the Black American community. Yet obstacles continue within the Black American community. History of injustice, marginalization, vulnerability, and lack of empowerment continues. Black Americans continue to have inferior education, feel unable to speak for themselves, and have underlying fear and mistrust of the medical system. They feel “God knows what is best.” They have given up their rights and do not realize what they have lost.

Education can be an essential role in combating health disparities. Black Americans (more men than women) receive less education regarding healthcare than Caucasians (American Cancer Society, 2005; Kafele, 2004; Villarruel, 2006). Many Black American men also lack health literacy skills and education like accurate screening information or are unaware of strategies to treat common diseases (CDC, 2007). Healthcare screenings can be a primary method for extending the life expectancy of an individual; yet, few minorities participate in screening procedures on a regular basis (NHQR, 2004).

Research indicates African American males are 45% less likely to have a regular doctor visit and to see a doctor than Caucasian men (NHQR, 2004). The research emphasizes a critical need for effective healthcare education within the African American community. Freire (2000), an advocate of the importance of educating the oppressed, expresses an ideal educational model: “Knowledge is a gift bestowed by those who consider themselves knowledgeable upon those whom they consider to know nothing” (p. 122). Freire (2005) also stated:

> Education should allow the oppressed to regain their humanity and overcome their condition. However, the acknowledges that in order for this to take effect, the oppressed have to play a role in their own liberation. No pedagogy which is truly liberating can remain distant from the oppressed by treating them as unfortunates and by presenting for their emulation models from among the oppressors. The oppressed must be their own example in the struggle for their redemption. (p. 54)

The stressors that have reinforced the barriers that prevent Black Americans from participating in health-promoting behaviors continue to marginalize underserved populations. Organizations have betrayed the Black American community with misguided and unethical experiments (Adams, 2011; Katz, Russell, Kressin, Green, Wang, & Claudio, 2006). The youth of this culture may be the keys to rebuild an edifice of trust and confidence of Black Americans. Educators and researchers can introduce diversity and ethnicity into education interventions and forums at all levels of education beginning in grammar school. The Black American community could be encouraged to form a partnership with the medical community, which would serve to empower the elderly Black Americans. Empowerment is a factor to help decrease disparities in underserved minorities. A platform needs to be developed to discuss ADs, to address quality of life issues at the end of life, and to test multiple interventions to determine the best approach to highlight the increased need for persons to consider ADs. Such approaches may decrease disparities of the elderly Black American at the end of life.

If the elderly Black Americans are to benefit from the use of ADs, a choice of how they choose to spend their last days on earth is available to them. Education will need to focus on education. Educational programs will need to provide information encompassing elderly Black American traditions. Culture, vernacular, religion, and social support systems must be a foundation to build upon and utilize to accomplish this feat. Education, in the past, has been directed as a passive gesture by institutions and primary care physicians (PSDA, 1991).The participants in this research have said that institutions have provided little or minimum support for the use of AD documents. Yet, the U.S.

Congress mandated federal laws that institutions receiving Medicare/Medicaid funds are required to present AD documents to their patients (PSDA, 1991).

It is not enough to provide a booklet of information or send the patient home with information he or she cannot understand, with the expectation that the patient and/or family will be able to make educated decisions about preplanned end-of-life care. Even though most of the participants in this study completed high school, they had no notion of medical terms that are used in the medical profession or documents about ADs. The terms Persistent Vegetative State (PVS), resuscitate, Do-Not-Resuscitate (DNR), and parental nutrition are not familiar terms. How many lay people in many cultures understand these terms? The researcher has the benefit of understanding medical jargon and could explain such terms to my participants had they been interested. No one has ever taken the time nor interest in doing so.

The linguistic connection between the researcher and the participants added a vital element of comprehension and insight into the educational barriers prevalent in the elderly Black American population about ADs. The dialogue on the subject of any type of AD documents needs to include significant support systems and culturally appropriate educational interventions about ADs.

In-depth outreach programs are needed to augment the literature presented to Patients. Intensive education and teaching efforts are needed. Primary care physicians should include family dialogue and add social support personnel to their staff to accomplish this monumental task. Community education about the initiation and use of ADs may be a starting point for individuals to become engaged (Latson & Ramsey, 2006).

Trust/Distrust. The researcher did not find trust/distrust to be a viable theme within her participant group. Prior research on the issue of trust/distrust was not supported by this study (Belcher Kelly & Floyd, 2001; Coffman, 2004; -Smith et al., 1999; Degenholtz et al., 2002; Fried et al., 2006; Perkins et al., 2002). Past research supported that Black Americans are distrustful of the medical system due to experiments (e.g., the Tuskegee The Syphilis Experiment Stud they often avoid medical treatment and/or signing documents promoted by healthcare providers. The researcher did not ask questions about trust/mistrust. Such questions may have uncovered trust/distrust as a theme among these participants. Yet, trust was a necessary element for trust in healthcare providers, patients, and patients' support networks, in prior research. Thus, additional research on trust/distrust issues is needed.

Distrust among the youth in the Black American community may mean that young people in the future will have even less interest or motivation to complete ADs. One of the participants (Laree) made reference to distrust of doctors implicating the medical system by saying: "They just want you to take pills and stuff without even trying to find out what's really wrong with you."

Musa et al. (2009) recognized that trust in an individual physician was totally different than trust in doctors. Musa et al. also reported that elderly Blacks spent more time with their physicians than the younger generation of Blacks. Measures as reported by Musa et al. deserve consideration as a tool for the initiation of ADs research (Allen et al., 2011; Byrdet al., 2011; Durant et al., 2011; Hanet al., 2011; Scharff et al., 2010).

Burdens Financial/Other

The participants in this study verbalized, without prompting, that their financial costs at the time of their death were adequate. In addition, all the participants expressed they had someone to take care of their final needs when they died. Yet, most of the participants had not attempted to verbalize their wishes to anyone about end-of-life care. The thematic analysis of “burden” was approached by these participants from the financial aspect of dying. Thus, the participants inadvertently placed an unintentional and unrecognized burdens about end-of-life care on their family/significant others and healthcare providers. The question, directly or indirectly was posed by the researcher to the participants: “What would you want or not want when you die?” Many of the participants verbalized how they would not want to be a burden to their families/significant others. Yet, eight out of the nine participants had not made attempts to minimize the burdens on their families/significant others should they become incapacitated or terminally ill. However, they had thought about (and one had completed) prepaid funeral arrangements, were living within their budgets, and had considered what would happen to their belongings and property.

Research was conducted by Hiari, Miyasbita, Morita, Snajo and Uchitomi (2006) on the constituents of what a good death would be. Not being a burden to family was a main conclusion to their research. Other research conducted by Vig et al. (2002) share the same conclusion. Yet the researcher interpreted that the plans made would be inadequate when these participants became incapacitated that their dying expenses or were not adequate to be “taken care of.” Yet, only one of the nine participants had a pre-planned Funeral flan. Upon further investigation, the researcher learned that the pre-arranged funeral plan was created in 1984 and never completed. When the family inquired into the issue, they learned that the rates quoted in 1984 were not the same as they would be in 2011.

The participants were similar concerning lack of education, avoidance, and procrastination about decision-making about end-of-life issues. The participants' awareness of their age and their interpretations of what death might be served to reinforce feelings pertaining to death anxiety. Such avoidance defense maneuvers were interpreted by the researcher as a psychological defense coping mechanism to protect the participant against death anxiety. Coping has been defined as cognitive and behavioral efforts to manage demands that are appraised as taxing or exceeding resources of a person (Lazarus, 1984).

The researcher noted in her journal notes that throughout the interview sessions, the participants were showing what she translated as external signs of anxiety. Participants exhibited what is termed "choice anxiety" as the interview progressed (Downey, 2008). For example, things they exhibited or said were:

- Wringing of hands, Constance
- Excessive moving in the chair, Betty
- Slow and hesitant, Bobbie
- Trembling, Mr. Robert Lee
- Teary eyed, Marie
- Betty putting her head into her hands
- "I have a long time to live," Emma.

Anxiety in itself is considered a normal reaction to stress/fears that will lead an individual to avoidance (Weiller, Bisserbe, Maier, & Lecrubier, 1998). The non-verbal behavior of the participants increased as the researcher asked to questions such as, “What would you like doneor not done to you at the end of your life if you were not able to speak for yourself?” Thus, the participants were asked by the researcher to think about their mortality. Paul may have expressed the real sentiments of all the participants when he said: “We just don’t talk about that.”

The researcher perceived that the social support as described by the participants may be burdensome to families and significant others. By not addressing the issues of ADs and end-of-life care, loved ones, significant others, family, and others were likely to become burdened when the participant became ill. Social support from friends and family increases well-being, improves quality of life, and decreases anxiety in matters related to healthcare decisions. Yet, the dependence on elderly Black Americans for their family/significant others to be left with end-of-life decisions may also be burdensome to families. Social support from medical providers can contribute to the confidence an individual has in healthcare systems (Sammacro & Konecny, 2008; Manning-Wash, 2005), but lack of planning may also become burdensome to healthcare personnel as they struggle with how to advise/help families when end-of-life healthcare decisions have to be made. Social support has been described as an emotional blanket and a necessary component for adjustment to change in our everyday realities. Social support was a major component in all of the participants’ lives concerning life and death issues (Koert, Borgen, & Amundson, 2011). The participants felt their relationship with family members would ensure their remains in matters of death would be adequately taken care of.

Responsibility and Social Support

Findings from this study support literature about the positive effects of social support and culture to maintain a positive quality of life, especially in the vulnerable elderly Black American population (Antonucci & Sherman, 1997; Lincoln, 2000; Sammacro& Konecny, 2008; Manning-Wash, 2005; Koert et al., 2011; Utsy, Bolden, Lainer, & Williams, 2008). The fabric of social support is intertwined between other coping mechanisms of African Americans. The research conducted by Utsy et al. (2008) concluded that spiritual and collective coping factors, which included social/family support, were significant predictors of positive quality of life outcomes in the African American community.

When the participants were asked, "What would you want if you are unable to speak for yourself, if you were incapacitated (explained in a way that the participants could understand)?,"the participants mentioned several things. Above all was that the participants named loved ones who they expected to make the determination of what the participant may want if the participant was rendered in a PVS for them. Yet, the participants have not verbalized their wishes with that person or persons that would serve as their surrogate. A surrogate is a substitute person, usually a significant other, spouse, close relative, or child, who is named in the event something happens to an individual, physically, emotionally, and/or psychologically. The surrogate would make decisions on that person's behalf if the person is rendered incapable to make life-altering decisions about matters of health or finance (see figures 13 and 14).

The term surrogate has taken a 180 degree turn since the advent of surrogacy and parenting in the case of "*Baby M.*" Melissa Stern was born March 27, 1986, and given a pseudonym Baby M. Baby M was conceived by artificial insemination. The donor sperm was provided by the biological father. The biological mother of Baby M, Sara Elizabeth Whitehead, gave up parental rights of Baby M after delivery and rendered to the Sterns. The surrogacy of the biological mother and the biological father entered into the prearranged agreement due to medical contraindication of Mrs. Stern.

Within 24 hours of relinquishing parental rights, the biological mother wanted Baby M back. The Sterns refused and fled the state. The Supreme Court remanded the case to family court. The lower court awarded William Stern custody and Mary Beth Whitehead visitation (Steinbock, 1988).

How many of us take surrogates for granted? Do we assume that a "surrogate" exists? Is a person's surrogate aware of the responsibility that has been placed on them? Is there an unspoken determination of an individual that will serve as a surrogate for another?

Through the questioning by the researcher, the participant identified the individual who was expected to serve as the surrogate. The researcher interpreted the nature of the role that the surrogate played in the life of the participants in this study as described below.

"My surrogate"

Composed in the limits of my reality
the individual is a concrete entity; I know that because
they always appear in my time of need.

I know they are real, because I have locked

them in that box in my virtual mind.

Yet they come and go as they please.

They do not need to speak;

they do not need to acknowledge their existence.

For I know they are always there.

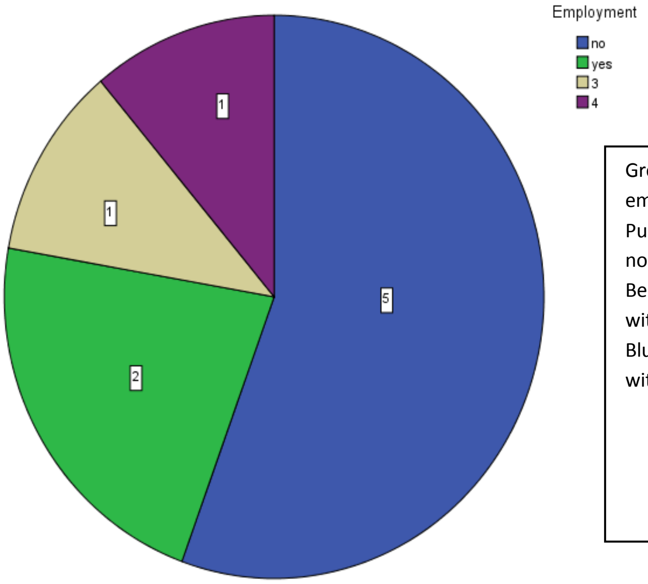
I never have to call on them when I need them

because they always appear in the nick of time

It is my insecurities that cause me to check on that “box”

from time to time for comfort.

Flenyol, 2012



# of Participants
= Count

Green = Sporadic, part-time employment, no benefits
Purple = Worked full-time, retired, no benefits
Beige = worked part time, retired, with benefits
Blue = worked full-time, retired with benefits

Figure 12.The participants' past/present employment status

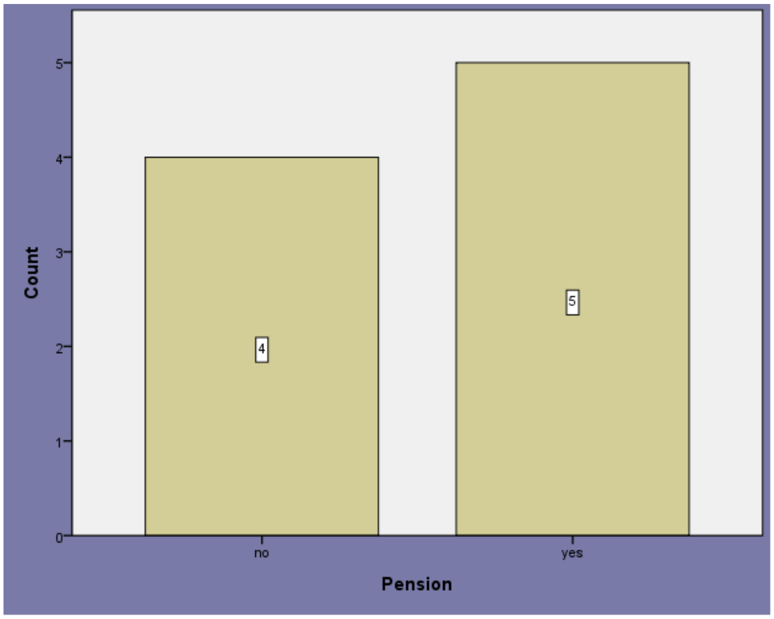


Figure 13.The participants receiving retirement pension.

Religiosity/Spirituality

The researcher recollects the presence of comfort and consolation as the participants described their relationship associated with religion and death. Religiosity/spirituality was a major theme that influenced the participants' feelings about death and their lack of need for an AD. Johnson, Kuchibbatla, and Tulsky (2008) concluded that religious beliefs may be in conflict with ADs for African Americans. The researchers report that the African Americans in their research believed that God determines when and how death will occur. Their research findings suggest that African Americans used in their study negate the need for an AD at all. Other researchers, in past research, have concluded that: religiosity/spirituality is one of the most prevailing spheres within the Black American culture (Warnke, 2009). Although the complexity of decisions to elicit the use of ADs is multi factorial, researchers support the thought that religiosity/spirituality may be the most prominent dynamic aspect of that decision (Erikson &Erikson, 1997; Holt &McClure, 2006; Joseph, 1998; Johnson et al., 2009; Johnson et al., 2008; Pargament & Mahoney, 2002; Rawlings-Anderson, 2004; Wheeler et al., 2002).

Fatalism (sub-theme of religiosity/spirituality). Fatalism is the belief that death is inevitable, and there are no other means that can dissuade its finality. The concept of fatalism was discussed by Powe and Finnie (2003) who suggested that fatalism develops over time and is associated most closely with medically underserved populations. Fatalism was a theme/factor reported by past researchers as one solution to cope with death issues. The researcher interpreted fatalism as a sub-theme of the theme of religiosity/spirituality due to the way the participants presented the subject to the researcher.

An attitude of fatalism negates any need for making decisions relating to health issues. Fatalism (or “God or family knows best” attitude) was ever present in the participants in this study. Participants avoided planning for end-of-life care. The result seemed to be an all-encompassing coping mechanism of protection or avoidance. The researcher identified protection or avoidance also as an overriding theme in all participants. Other researchers have reported similar findings (Blackford, 2003; Freeman, 1989; Gulanick, 2003; Powe, 1995, Powe & Finney, 2003; Riley et al., 2004; Thobaben, 2008; Warnke, 2009; Wheeler et al., 2002).

Marie, the participant whose husband died while Marie was forced not to seek help for her him, said, “Joe said there was nothing that could be done for him.” Unfortunately, Marie could not know what her husband’s perception of that experience was for him. For example, the researcher wondered, was it out of his condition, his lack of financial and social support systems, fatalism, religion/spirituality, or something completely different that determined attitude?

Pain/Discomfort (a sub-theme of religiosity/spirituality).

Pain, discomfort, and being comfortable and not in pain were global perceptions shared by all the participants in this study when they talked about end-of-life concerns. Although only one of the participants actually possessed an AD that specifically addressed the pain/discomfort concern, the other participants shared the common issue. A sub-theme of pain/discomfort was present when participants made inferences about pain/discomfort to describe their wishes, fears, and concerns associated with death and dying. However, the participants that stated they did not want to be in pain or to be uncomfortable when they died also vocalized concerns about their family's perception of the state of their pain. Most of the participants shared the same feelings about pain. The researcher interpreted any inferences to pain/discomfort as an attempt to meet basic physiological needs (Maslow, 1970). Maslow (1970) addressed this basic need as a need for physiological comfort. To be pain free or comfortable can be compared to being hot or cold. To be in pain would be contrary to Maslow's hierarchy of basic needs.

Avoidance

The concept of understanding the behaviors of the elderly Black Americans' perceptions about ADs was a complex journey into the interpretations as seen through the researcher's lens. Fear of the unknown, lack of knowledge, religious convictions, and social support systems are very real entities to individuals' experiences, real or imagined. Fear is a natural phenomenon, an armor of protection against adversity that we perceive and a coping mechanism (Siegel, 2006).Fear can occur without any conscious input or provocation by an individual. The mechanisms of fear as these mechanisms relate to death anxieties and resultant avoidance have become obstacles in the wake of elderly Black Americans preparing for their end-of-life.

The themes, sub-themes, and the thematic clusters identified the participants' story. Avoidance was at the height of thematic emersion. Avoidance was a subconscious process that allowed the participants to escape anguish and pain associated with confronting the process associated with death and death anxiety. The use of avoidance is directly related to a problem. When an individual uses avoidance as a coping mechanism, it is a way of manipulating the environment perceived as intimidation or harmful. Avoidance is a way to minimize the effects of the situation that initiated the avoidance measures to be employed. Avoidance was interpreted as a coping mechanism (Neimeyer, Wittkowski, and Moser, 2004).Becker (1997) explained death anxiety as an individual's attempt to deny death and to keep death anxiety under control. Becker believes that many beliefs and practices are in death denial and thus reduce death anxiety. Becker labels self-esteem and religious beliefs as a large part of reducing death anxiety fears.

Figure 15 below illustrates the themes discovered in this research study. Avoidance was the dominant, overriding theme explaining the relationship with other themes and sub-themes. The emerged themes parallel prior research and support the researcher's findings. The results from this study are suggestive of the importance for clinicians to understand how coping resources affect mental health in individuals dealing with race-related stress. When considering coping resources, prior research findings have established that racial identity is a major determinant in the type of coping resources used (Hurst, 2010).

Neimeyer et al. (2011) found that men reported greater fear and avoidance behaviors compared to women and Caucasian individuals; gender and ethnicity were strong predictors of avoidance. In this present research, 22.2% of the participants were males. All the males indicated these explicit behaviors when the researcher asked them about death. Paul said: "We just don't talk about that. You know what I mean." He also said: "He's (referring to God) the one that puts you asleep and wakes you up." In addition, the statements made by Paul reflect his religious and fatalistic convictions in connection with death issues. Mr. Robert Lee had similar beliefs as Paul regarding avoidance of death issues. Mr. Robert Lee said: "When it is over, that's it." In response to the implications of Mr. Robert Lee's responses, the subject was finalized and finished, and there was no more to be said about death. The females in the research displayed behaviors that the researcher interpreted as avoidance. The researcher interpreted avoidance as more complex and abstracted than the male participants in this study.

Bobbie, Georgia, Constance, Marie, Laree, Betty, and Emma said many things that have already been stated that consequently lead to the path of avoidance. As age increases, life that we confront the realities and situations that stimulate reflection of our past life and inquisition about the future. The matter of death is met as debilitating illnesses and disease associated with aging cannot be tossed away. The complexities of challenges associated with accepting death would be embraced if death were like that old shoe in the closet. We know it is there it is just there. It is much easier to push the fear and anxiety away into the comfort of what we choose—not to know, let our significant others take care of "it," our souls and our God, and accepting that it is going to happen. (see Figure 15)

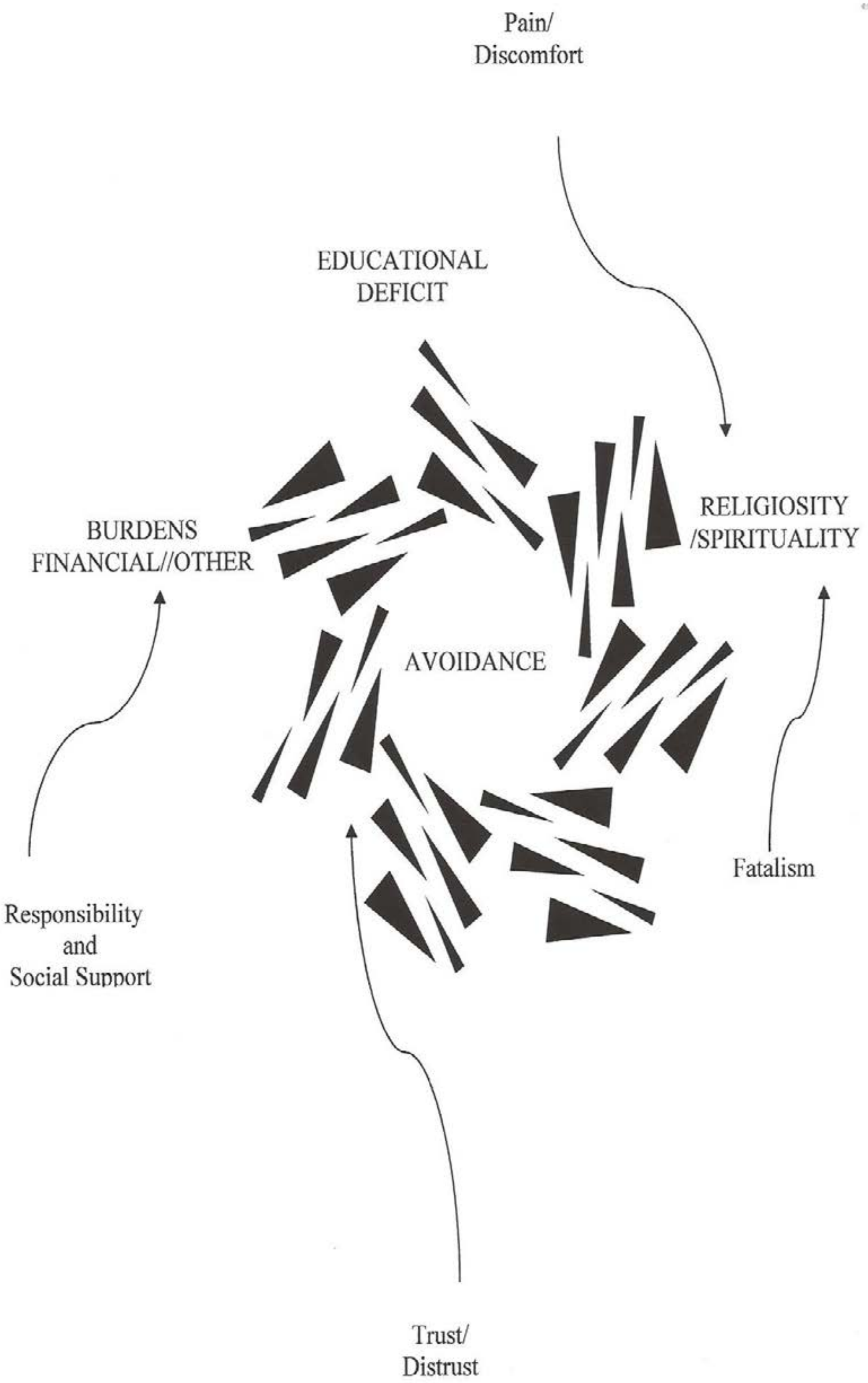


Figure 15.Flenyol's interpretation of the overriding theme of avoidance.

Implications/Significance of the Study for Nursing Knowledge

The researcher reflected on her insight and feelings due to past negative experiences of painful and anxiety-ridden decisions in her work as a nurse anesthetist. Particularly troubling were the struggles she observed surrounding the death of elderly Black Americans. The researcher was constantly and continually reflecting on her emotions as she watched these struggles unfold. As the researcher attempted to rid herself of her biases about ADs, she sought to add to the body of nursing knowledge on the subject of advanced end-of-life care planning for the elderly Black American. The researcher's goal was to gain knowledge and insight to improve quality of life at the end-of-life for the elderly Black American.

Knowledge gained from this study supported knowledge from previous literature. The concept of an AD /preplanned end-of-life care is not working for participants in this study. As we move further into the 21st century, the issues about providing medical care to all are going to be questioned further. There continues to be a need for reflecting about the healthcare system at the end-of-life and the lack of knowledge by nurses and other health professionals as to how to address end-of-life care of Black Americans. Unfortunately, in issues surrounding death care, the researcher holds a pessimistic view about quality of life at the end-of-life for the elderly Black American. Unless factors associated with improving the quality of death issues are addressed, there will be overwhelming flood of demands placed on every aspect of the medical system. As Black Americans are living longer, not having an AD plan can be detrimental to this underserved population. Medical needs will increase with elderly Black Americans, and comorbidities will place additional stress on an already insufficient economy (*Healthy People 2010*, 2000).

The perceptions of elderly Black Americans and their reasons for not participating in preplanning for end-of-life care appear to magnify and possibly multiply disparities that prevent end-of-life care for this underserved population. The causes are many and include a lack of education, misplaced burdens, dependence on social support structures, and strong religious/spiritual convictions that appeared to be linked to fatalism and pain/discomfort concerns.

Implications/Significance of the Study for Education

Nursing curricula could increase open discussions about death/dying by using culturally appropriate introductions. These discussions are important, not only for nurses, who probably are the healthcare member that will spend the most time with the patient, but throughout all professional courses. Particularly with nursing students, cultural issues must be considered as patients and families struggle with decisions that are culturally bound. Patients and their healthcare surrogates should be approached with knowledge of culturally appropriate communication.

Professional regulatory bodies and institutes of higher education will be the pacesetters needed to aid in achieving the goal of increasing the utilization of ADs with open communication and skilled training programs. This was the only orientation of the participants to ADs. Professional regulatory bodies and higher educational institutions will be the tool needed to aid in achieving the goal of increasing utilization of ADs by elderly Black Americans. Times have changed. Technology has invaded every aspect of our lives.

As mentioned earlier, institutions that receive Medicare funds are to engage their recipients in open discussion about ADs. All but one of the participants (at a later date than originally interviewed) had been exposed to conversation about ADs. Georgia, who had an AD needed to change her primary care physician (Primary Care Physician). Georgia, the researcher's neighbor, contacted the researcher to show the researcher documents given to Georgia during her initial evaluation with her new PMD. A perfect opportunity is presented to all of these participants when they visit their PMD, clinic, or dialysis center, await radiology and laboratory testing, or are admitted to the hospital. A video in those waiting rooms would be the perfect forum. Patients are usually bored while waiting for procedures. The researcher is assured that Florida medical facilities operate pretty much in a similar manner. Patients are going to be present at the medical facilities for at least an hour.

New attitudes among the younger generations can be augmented with educational outreach programs for their elders in discussion of ADs. The younger generations of Black Americans are ideal fulcrums to use to introduce ADs to their elders. The younger generation of Black Americans has undoubtedly quadrupled educational objectives, exposure, and opportunities available to them. Elderly Black Americans probably are not afforded the same educational opportunities. Younger Black Americans have probably assimilated into a more Eurocentric culture than their elders. The technology advances and changes in cultural attitudes and a blended culture provide an ideal environment to begin open discussion about ADs with their elders.

elderly Black Americans could benefit from death, dying, and preplanned end-of-life issues if those issues were introduced in nursing undergraduate curricula. The focus would be on redirecting younger generations on the subject of preplanned end-of-life care. The younger generation can break the negative bonds of antiquated cultural norms.

Implications/Significance of the Study for Nursing Practice

As more evidence-based knowledge is introduced into the profession of nursing, challenges will increase if we are to decrease the gap in promoting preplanned end-of-life discussions with this underserved population. Although distrust of the medical system was not discussed by participants in this study, nurses who engage in a reciprocal relationship with Blacks may build trust and influence with vulnerable groups and encourage them to consider the use of ADs. Distrust of the medical community continues to be one major obstacle for the lack of use of ADs in the African American community (Williams, 2010).

Nurse Practitioners may be able to shift existing paradigms of care from socially Eurocentric models and understand what it means to be socially, psychologically, physically, and emotionally “Black,” living in a White Eurocentric environment. The depiction of the elderly Black American in our society is very different from any other ethnic minority (Smedley, Stith, & Nelson, 2010). In the researcher’s own practice, she cautions nurses not to assume stereotypical impressions of racial similarities with stereotypical impressions. Nurses face new challenges in caring for multi-ethnic populations. The researcher’s concerns are not a question of race. As an example, the researcher is a Black American. The researcher does not have to go far to discover other Black Americans that have totally different cultural and ethnic beliefs than the researcher. There are Caribbean, Haitian, etc. groups in the Black community as well as White. It is not race that explains the essential differences between Blacks' end-of-life preplanned care, it is ethnicity (Daaleman, Emmett, Dobbs, & Williams, 2008).

South Africa has a very large population of members of the "White" race. So it would be an oxymoron to consider their descendants, born in America as African Americans. It is sometimes assumed that a person is of a particular race or ethnicity because of the way one may look. The basics of communication are often overlooked. Asking the patient about his or herculture may be only action that may produce a myriad of information about preplanned end-of-life care preferences.

The information the nurse receives in clinical practice could be the influential factor that may add to the nurse's ability to provide culturally appropriate care for the ethnically different patient. Nurses can involve all members of the healthcare team, especially the patient's primary care physician. Jackson et al. (2009) suggest that patients respond more positively and more openly when physicians initiate discussions about ADs. Nurses will need to be aware of their own prejudices and nuances to be effective role models in the active role of caring for elderly Black Americans especially related to their need for preplanned end-of-life care (Utsey, Ponterotto, & Porter, 2008).

Implications/Significance of the Study for Nursing Research

The results of many research studies have documented that health disparities exist within the Black American community. Research now needs to be focused on an "out with the old in with the new" mentality. The change should be reciprocal between the nurse, patient, and the patient's support system. Ingrained cultural attitudes are a part of all of us. Nurse attitudes about stereotyping and profiling "others" can interfere with the care delivered to our patients. Relationships between patients and nurses should be geared and built upon plausible research that recognizes our society as colorblind.

Evidence-based research on the use of ADs by the elderly Black American can be extended from the classroom. Activities must be disseminated through the communities and in clinical settings. Knowledge discovered from classroom and community interventions may also serve as stepping stones to build cohesive relationships between nurses and other healthcare personnel who are caring for patients at the end of their lives (Carlson & Chamberlain, 2004). PhD-prepared nurses and DNP-prepared (ARNP) nurse practitioners can lead the way.

Implications/Significance of the Study for Nursing Health/Policy

Over 20years since the inception of the initial laws were enacted, the issues for end-of-life preplanned care has not increased by the initiation and the use of ADs in the elderly Black American population. The Black American is an underserved group of people. Available medical dollars are used to deliver the most efficient care at the most resourceful cost. Technology, advances in medicine, and potential for socialized medicine are factors that will potentially mandate the use of AD. now is the time to act to empower the elderly Black American communities with the education and information to make well-formulated decisions about their end-of-life care preferences (Corbie-Smith et al., 1999; *Public Law 111-148., 2010).*

The impact of legal, financial, and ethical regulatory policies are going to be mandated, as a result of changes in the national healthcare policy. The decision about end-of-life care may be removed from the individual who does have an AD and placed into the hands of the economic policy makers. The choices of Black Americans about end-of-life care may not be available for the elderly Black American community(Searight& Gafford, 2005).

In general, Black Americans prefer more aggressive end-of-life care when compared to Whites. The dissemination of information gained by evidence-based research will be needed to increase the use of ADs by the elderly Black American community (Decker & Reed, 2005; Winter et al., 2003). Thus, past preferences of African Americans for end-of-life care and often “futile” treatments will be cost prohibitive (Bangtson et al., 2005).The government is involved in helping to decrease health disparities in the African American community. But, research has documented evidence that previous measures are not productive enough to change the use of ADs by African Americans (Yaggy et al., 2006).

Provisions in the Patient Protection and Affordable Care Act (2010) required the centers for Medicare and Medicaid Services to conduct a demonstration program, known as Independence at Home. The program was tested in home-based primary care models (Public Law 111-148, National Healthcare Forum (2010). On a national level, conferences have explored end-of-life care in African American community. In the future, there are likely to be fiscal requirements to cut these types of programs. Such cuts will further limit preplanned end-of-life care for African Americans.

Dame Cicely Mary Saunders (1918-2005) helped the dying and terminally ill end their lives in the most comfortable ways. Dr. Saunders is best noted for her work in the “The Hospice” movement. The words of Dr. Saunders describe the foundation of her work. "*How people die remains in the memory of those who live on."*

Dr. Dame Cicely Saunders

Strengths and Limitations of the Study

The strength of this study lies in the research question, “What are the perceptions of elderly Black Americans about Advance Directives?” along with the themes that evolved from participants’ words. Additionally, the use and adherence to van Manen’s (2002) human science research methodology approach along with Miles and Huberman’s (1994) exploratory descriptive methodology were strengths that promoted research rigor. These methods led to the researcher’s interpretation of the themes that emerged and strengthened the possibility for transferability of findings.

Recruitment of Black Americans for medical research continues to be limited despite incentives to increase their participation in medical research (Slomka, Ratcliff, McCurdy, Timpson, & Williams, 2008). Recruitment in this study was only possible because of the researcher’s ethnicity, her close ties to Black Americans in her community, and snowball sampling. Yet, due to the limited number of African Americans that agreed to participate, the sample was a limitation. However, the participation of at least nine elderly Black Americans and their willingness to speak with the researcher was strength. The homogeneity of the sample did limit the transferability of results.

Age of participants was both a limitation and strength. Although age may have been a limitation in this study, it may have also been an asset. The target population in this study was individuals within the elderly Black American population with a need for ADs. The researcher states “a need for ADs,” since research studies have supported the use of ADs as one way to decrease health disparities in underserved minority populations. The researcher was able to answer the “why/why not” of the research question, “What are the perceptions of elderly Black Americans about ADs" through an exploratory approach. The information and knowledge gained from this research can be used to empower elderly Black Americans by engaging them in discussions about how they want to die. The strength of this research lends itself to newfound knowledge can be used to break the bonds that inhibit elderly Black American from using ADs. Although ADs are legal documents, although not ideal, discussion with social support persons might become the more simple uncomplicated method to achieve initiation of ADs. Congress has advocated the use of ADs, nurses encourage the use of ADs, evidence-based research supports AD use, and healthcare policy will soon mandate and <u>enforce</u> the use of ADs as a means to contain the use of healthcare dollars.

Information within the Black American community culture, in the past, has been passed from one generation to the next. The Black American youth of today have been acculturated into present day society. The younger generations of Black Americans have opportunities to acquire information modalities that their parents and grandparents could not imagine. The age gap may have produced an unlinking of older cultural values and norms that were passed from one generation to the next. But in contrast, it is the youth that have the tools necessary to carry to their elders about ADs/preplanned end-of-life care. Knowledge and education are the basis of any change. Knowledge is empowerment (Freire, 2000).

The research results from this and previous studies revealed that elderly Black Americans have engrained cultural beliefs and values. Black Americans are spiritual; they rely on their significant others to make their end-of-life care decisions; they have fatalistic attitudes that may or may not be connected to their religious beliefs; they prefer more aggressive end-of-life treatments (Beck et al., 2002; Bradley,2005; Bullock, 2006; Flenyol, 2012; Waters, 2000).

One limitation of this research study was the use of a purposeful sample of participants that reduces the transferability of results to other groups. The purposeful sample of participants were from a small sector of elderly Black Americans living in Ft. Lauderdale, Florida. “Black” American refers to one select group. South Florida contains innumerable groups of diverse minorities within the Black American community. Since previous researchers’ results did not confirm the delineation of which elderly Black American group was utilized, the results from this study may or may not be transferrable to the other diverse groups.

Recommendations for Future Study

Public policy and opinion support autonomous medical decision making, which is also validated by the enactment of the PSDA (1991). However, research on factors that may influence health-related decisions is limited within the elderly Black American community (Allen et al., 2011). Elderly Black Americans have engrained cultural beliefs and values that in the past have been passed down from one generation to the next. Research focused along different generational groups could reveal a more in-depth understanding and comprehension that accounts for the low initiation/ adaption of ADs by the elderly Black American population.

Intervention research designs may be more meaningful to test if educational interventions will increase the use of ADs. Two of the participants from this research study requested AD documents. However, the researcher interpreted the action as a gesture of kindness to her and <u>not</u> as a preliminary thought or motivation to sign ADs.

The researcher has not contacted the participants since their last verification encounter, nor have any of the participants asked the researcher for any additional information although she encouraged them to contact her with any questions or requests for AD documents.

Conclusions

This exploratory research study offered insight and a foundation for a better understanding to improve quality of life at the end-of-life for elderly Black Americans. Hopefully, the knowledge gained might be transferrable to include other Black Americans (Rubin& Babbie, 2009) and perhaps persons from other cultures who have not signed ADs. Measures available today, such as incentives allocated to physicians that were enacted through Medicare/Medicaid as a means to increase the use of ADs by underserved population, are not working.

This research focused on the elderly participants. Nurses need to be active participants involved in evidenced-based research to solve the complex challenges of rendering end-of-life care for the underserved elderly Black American community. A multidisciplinary team approach concentrated on providing sufficient training to identify cultural and ethnic sensitivities may promote end-of-life care planning. Communication and education with other team members are essential tools necessary to deliver optimal culturally appropriate end-of-life care.

In conclusion, all of the participants exhibited behaviors that were interpreted by the researcher as “avoidance.” Thus, avoidance was the overriding theme of the study. The themes and subthemes supported the results. The presentation of ADs necessitates a change in the elderly Black American population. Initiatives are now needed to continue the work to increase the elderly Black Americans’ empowerment. If Black Americans are encouraged to speak for themselves and to inquire about ADs and use them, perhaps they will have a chance to have optimal quality of life at the end of life (Winter et al., 2003). Evidence-based research results support cultural competence as a major factor that can improve the quality of preplanned end-of-life care in an effort to help decrease health disparities in the elderly Black American population.

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APPENDIX A

IRB APPROVAL

BARRY University

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300-756¯6000, ext. 3020
fax 305-599-3025

OFFICE OF THE PROVOST
INSTITUTIONAL REVIEW
BOARD

Research with Human
Subjects Protocol
Review

Date: July 14, 2010

Protocol Number:[redacted]

Title:A Qualitative Study on the Perceptions of Elderly Black Americans about Advance Directives

Meeting Date:June 16, 2010

Researcher Name:[redacted]
Address:

Faculty Sponsor:[redacted]

Dear [redacted]:

On behalf of the Barry University Institutional Review Board (TAB), I have verified that the specific changes requested by the convened IRB June 16, 2010 have been made.

It is the IRS's judgment that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with requirements and that the potential benefits to participants and to others warrant the risks participants may choose to incur. You may therefore proceed with data collection. As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved by the IRB. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form.

It is a condition of this approval that you report promptly to the IRB any serious, unanticipated adverse events experienced by participants in the course of this research,
whether or not they are directly related to the study protocol. These adverse events include, but may not be limited to, any experience that is fatal or immediately life-threatening, is permanently disabling, requires (or prolongs) inpatient hospitalization, or is a congenital anomaly
cancer or overdose.

The approval granted expires on July 12, 2011. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with and 1RB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request a progress report from you approximately three months before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the IRB, please can the IRS point of contact, [redacted]. Finally, please review your professional liability insurance to make sure your coverage includes the activities in this study.

Sincerely,

[redacted]

[redacted]

Research with Human Subjects
Annual Report

Researcher: [redacted]

Protocol Number: [redacted]

Protocol Title: A Qualitative Study on the Perceptions of Elderly Black Americans about Advance Directives

I. Number of subjects who participated in the project since the last report (or since the last report (or since approval, if the first report).

Nine (9) subjects participated in this project since IRB approval

2. Did subjects have any adverse reactions to research conditions? (if yes, explain.)

The subjects did not show any signs of adverse reactions from the research conditions. As described in the Protocol: Page 105, Appendix D, "The risks of involvement, and as stated on the "Consent faun." Appendix B.

3. State whether informed consent forms for all participating subjects are on file in location specified in the protocol. (If no signed informed consents were used, state "Not Applicable.")

Informed consent forms, for all participants are on file as specified in the IRB protocol as follows: Consent forms are being kept in locked storage separate from other research data. The information is stored according to Barry University's IRB and will be destroyed within five years after completion of the study.

4. Actual or estimated completion date. Completion of data collection date was June' 2011

Dale E. Flemyol	July 19, 2011
Signature of Principal tor	Date

5. If you are renewing for another year, please attach an original of your consent letter so that it may be validated with a stamped date and returned to you for you to continue collecting data. Thank you.

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Dale Flenyol** successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 05/20/2010

Certification Number: 450965

BARRY
UNIVERSITY

11300 NE Second Avenue
Miami Shores, FL 33161-6695 phone
305-899-3020 800-756-6000, ext. 3020
fax 305-899-3026
www.barry.edu

OFFICE OF THE PROVOST
INSTITUTIONAL REVIEW

Research with Human Subjects
Annual Report

Date: June 24, 2011

Protocol Number: 100613
Title: A Qualitative Study on the
Perceptions of
Elderly Black Americans about Advance
Directives

Approval Date: July 14, 2010

Name [redacted]
Address: [redacted]
[redacted]

Faculty Sponsor: [redacted]

Dear [redacted]

According to the Barry University Policy and Procedures for the Protection of Human Subjects in Research, and the Code of Federal Regulations, research projects and activities which have received approval from the Barry University Institutional Review Board IRB) must be reviewed at least annually after initial approval. Please complete the attached Annual Report Form and submit to:

[redacted]
Academic Affairs - IRB
Barry University, LaVoie 110
11300 NE Second Avenue
Miami Shores, FL 33161

If no response is received within thirty days, approval for the continuance of this study will be withdrawn.
Note:
Federal funding agencies require IRB approval on file for each study to be current (i.e., updated annually) in order for funding to continue.
If you finished your study before the anniversary date, the report still has to be completed and returned to us as it must be retained for audit purposes.
Please call the IRB Chair if you have any questions concerning the annual report.

[redacted]

[redacted]
Chair Institutional Review Board
Associate Dean, SGMS & Program Director, PA Program Barry University - Box SGMS - 11300 NE 2 Avenue Miami Shores, FL 33161

APPENDIX B

BARRY UNIVERSITY INFORMED CONSENT

Your participation in a research project is requested. The title of the study is “A Qualitative Study on the Perceptions of Black Americans about Advance Directives.” The research is being conducted by Dale E. Flenyol, CRNA, M.S, a student at Barry University's doctoral program at the Division of Nursing, and is seeking information that will be useful in the field of clinical nursing. The aim of the research is to explore elder Black Americans’ perceptions about Advance Directives. Advance Directives are legal documents to assist persons to describe the type of care they want to receive at the end of life. In accordance with this aim, the following procedures will be used: semi-structured, audiotaped individual interviews. We anticipate the number of participants to be no more than 20.

If you decide to participate in this research, you will be asked to do the following: agree to an audiotaped individual interview at a mutually agreed upon location and time. The interview between you and the researchers will last no more than one (1) hour. At the end of this interview, you will be invited to meet a second time with the researcher to confirm accuracy of the transcripts of your interview and to add further information. This second meeting will not be audiotaped and could take place in person or if mutually agreed, by phone or email. At the beginning of the initial interview, you will also be asked a few questions such as your gender and age. This information will be completed by you and the researcher together. The total time commitment for this study is anticipated to be no more than 1 hour for the initial interview and the possibility of a second interview to last no longer than ½ hour. Following the initial interview, you will receive a $20 gift certificate as a token of appreciation for your time.

Your consent to be a research participant is strictly voluntary and should you decline to participate or should you choose to drop out at any time during the study, there will be no adverse effects to you. You have the right to refuse audiotaping or to have the tape turned off at any time during the interview. You also have the right to refuse to answer any question(s).

The risks of involvement in this study are expected to be minimal; however, because of the topic to be discussed, Advance Directives, or specifically your thoughts about end of life care planning, the discussion may evoke feelings of increased anxiety or discomfort during or following the interview. Therefore, at the beginning of the first interview a written list of community services will be provided to you for follow-up in the event you need it.

Although there are no direct benefits to you, your participation in this study may help nurses and other health professionals increase our understanding about elder Black Americans’ perceptions of Advance Directives. The ultimate goal of this research is to improve health professionals’ communication about Advance Directives with elderly

Black Americans. Such information may be in developing strategies that may lead to the improvement of end of life care for elderly Black Americans. Some indirect benefits might include time spent with the researcher and the opportunity to voice personal feelings and beliefs about the topic. As a research participant, information you provide will be held in confidence to the extent permitted by law. Any published results of the research will refer to group averages only. Quotes from the interview will be cited for illustration purposes only and no participant names will be used in the study. Before the interview begins, you will choose a pseudonym (fake name) that will be used during the interview and on transcriptions of the interview. All data will be kept in a locked file in the researcher's office. Audiotaped interviews will have no identifiers of participant's names and be kept separate from consent forms and from the coding system being utilized in this study. A transcriptionist will be used to transcribe the audiotaped interviews verbatim. The transcriptionist will be required to sign a confidentiality statement prior to their access to the audiotapes. Audiotaped interviews will be destroyed within 4 days after transcription and after you have confirmed the information during the second interview should you decide to complete a second interview. If you choose not to participate in the second interview, the audiotape will be destroyed 4 days after the transcription is complete. Your signed consent form and demographic sheet will be kept separate from the data collection records. All data will be destroyed after five (5) years.

If you have any questions or concerns regarding the study or your participation in the study, you may contact me, Dale Flenyol [redacted] dale.flenyol@mymail.barry.edu or my supervisor, Dr. Sandra Walsh, [redacted] swalsh@mail.barry.edu or the Institutional Review Board point of [redacted] If you are satisfied with the information provided and are willing to participate in this research, please signify your consent by signing this consent form.

Voluntary Consent

I acknowledge that [redacted] has informed me of the nature and purposes of the study and that I have read and understand the information presented above, and that I have received a copy of this form for my records. I give my voluntary consent to participate in this study.

______________________________ ______________________________

Researcher Date Participant Date

APPENDIX C

CONSENT CHECKLIST

NOTE: The consent form should be written in the *third person* (i.e., “your participation…,” or “your child’s participation…”)

N/A YES NO

___ _X___ __ 1. Is the consent form written in lay language. The consent form should avoid jargon and should be written simply for understanding the contents.

___ _X_____ 2. Is coercive language avoided (e. g. , if you participate in this research, we will be well on the road to finding a cure for AIDS)?

___ _X_____ 3. Is the participant fully advised of his or her rights? Is the consent form free of any exculpatory language through which the participant is made to waive any legal rights, including any release of the investigator, the sponsor, the institution, or its agents from liability for negligence?

___ _X_____ 4. Is an introduction of the researchers, their affiliation, and the purpose of the study and the expected duration of participation included?

___ _X_____ 5. Are descriptions of procedures included, including the expected duration of participation?

___ _X_____ 6. Is there a disclosure of available alternative procedures or treatments, if any that might be advantageous to the subjects? Remember, choosing to refrain from participating is an alternative.

___ _X_____ 7. Is there a description of any risks or discomfort to the participant?

___ _X_ ___ 8. Is there a benefits statement?

___ _X_____ 9. Is there a statement describing the extent to which confidentiality of records identifying the participant will be maintained?

___ _X_____ 10. Are the principal investigator and faculty sponsor's name and contact number given for answers to questions about the research study?

___ _X_ ___ 11. Is the anticipated number of participants given in the Consent Form as well as the protocol?

___ _X_____ 12. Is it disclosed that participation of the participant is voluntary and that he or she has the right to withdraw at any time without penalty?

___ _X_____ 13. Does the form provide for the signature of the consenting participant and the investigator?

___ _X_____ 14.Does the form state “Barry University, (Parent) Consent Form” at the top of the first page?

APPENDIX D

BARRY UNIVERSITY RESEARCH WITH HUMAN PARTICIPANTS

PROTOCOL FORMPROJECT INFORMATION

1. Title of Project
   A Qualitative Study on the Perceptions of

   Elderly Black Americans about Advance Directives

2. Principal Investigator

[redacted]

3. Faculty Sponsor

[redacted]

Signature: ________________________________ Date: ____________________

4. Research Sponsor

Barry University School of Nursing
11300 Northeast Second Avenue
Miami Shores, Florida 33161-6695
TEL: (305) 899-3800

5. Proposed Project Dates

Start June 30, 2010
End June 29, 2011

A. Project activity STATUS is:

_X NEW PROJECT

B. This project involves the use of an INVESTIGATIONAL NEW DRUG (IND) OR AN APPROVED DRUG FOR AN UNAPPROVED USE in or on human participants.
___ YES _X_ NO

C. This project involves the use of an INVESTIGATIONAL MEDICAL DEVICE (IMD) or an APPROVED MEDICAL DEVICE FOR AN UNAPPROVED USE.
___ YES _X_ NO

D. This project involves the use of RADIATION or RADIOISOTOPES in or on human participants.
___ YES _X_ NO

E. This project involves the use of Barry University students as participants. (If any students are minors, please indicate this as well.)
___ YES _X_ NO
___ MINORS

F. HUMAN PARTICIPANTS from the following population(s) would be involved in this study:

___ Minors (under age 18)
___ Abortuses
___ Prisoners
___ Mentally Disabled
___ Other institutionalized persons (specify)
___ Fetuses
___ Pregnant Women
___ Mentally Retarded
__X_ Other (specify) elderly Black Americans, 65 years and older, from a south Florida community

G. Total Number of Participants to be studied: 20

Description of the Project

1. Abstract

Background: Elderly Black Americans have specific cultural knowledge and beliefs related to Advance Directives (ADs). ADs address issues pertaining to preplanned end-of-life care. Literature reviews support that the majority of Black Americans do not have ADs.

Purpose: The purpose of this study was to explore the perceptions of elderly Black Americans about ADs. The use of ADs has been advocated as a measure to help decrease health disparities in minority, under-served, under-represented members of society.

Philosophical Underpinnings: Qualitative inquiry methods were employed as the philosophical underpinnings as described by Miles and Huberman, Leininger, and van Manen

Methods: The philosophical underpinnings of this study arose from a naturalistic paradigm. One-on-one, face-to-face, audiotaped interviews between the researcher and a purposive group of nine participants were the primary source of data collection, supplemented by field notes and observations. The data were reduced and coded until themes emerged to describe elderly Black Americans' perceptions about ADs.

Results: The transcribed interviews were analyzed. Four major themes emerged: educational deficit, burdens financial/other, religiosity/spirituality, and a dominant overriding theme of avoidance. The researcher also identified sub-themes of trust/distrust, responsibility and social support, fatalism, and pain/discomfort.

Conclusion: Themes emerged that were consistent with prior literature. Elderly Black Americans continue to be underserved recipients of healthcare and do not sign nor have knowledge of AD documents as compared to Whites. Nurses may use knowledge from this study as a template when issues arise from patients who are from "other" cultures.

2. Recruitment Procedures

A volunteer self-referral population of 20 elderly Black American adults, who may attend one of the Community Centers or Churches(see Appendix G—Recruitment Facilities) will be recruited. Potential participants will obtain information via a recruitment flyer (See Appendix I) posted on bulletin boards at the facility, or published in newsletters and/or church bulletins. Word-of-mouth or snowball sampling will also be used.

Any person interested will initially contact the researcher for further explanation and possible enrollment in the study. If the participant agrees and self-identifies as a Black American 65 years or older, a time and place, mutually agree on by both parties will be set for the first interview. At the beginning of the initial audiotaped interview, the researcher and participant will complete a demographic questionnaire sheet, the participant will be given a referral form labeled 'support information for participants (See Appendix L), and the interview will begin. The consent will be obtained according to approved IRB procedures; the participant will be given a copy of the consent. The researcher will have equipment with her to make copies. The researcher will be the sole data collector. The participant or researcher may stop the interview at any time; the participant may quit at any time; the participant may refuse to answer any questions or request that the audiotaping be stopped; the participant can refuse to have the interview audiotaped Any participant that does not agree to audiotaping will not be enrolled in the study.

In summary, inclusion criteria will be determined as follows:

- Black American, self-identified
- At least 65 years of age
- A resident of south Florida
- No present known life -threatening or terminal disease state.
- Cognitively stable, as determined by the researcher.
- Able to make their own decisions
- Able to read and comprehend the nature of the project.
- Willing for interviews to be audiotaped

Exclusion criteria will be determined as follows:

- "Blacks" that did not meet the specific criteria as noted for the purposive sample would not qualify. Example: Caribbean, Haitian, Cuban, South American, et cetera.
- Individuals who do not possess the cognitive ability to express their perceptions about end-of-life preferences (as determined by the researcher).
- Individuals under 65 years old.
- Individuals unable to speak the English language.

- Disqualified individuals by information on the demographic information (e.g. under the age of 65).
- Refuses for the interview to be audiotaped

3. Methods

A qualitative exploratory method will be used to describe the perceptions of elderly black Americans about Advance Directives (ADs). The researcher will contact Center Directors and/or Pastors from churches to arrange a meeting for the researcher to give information about the project, and seek permission to post a flyer in the facility or in publications such as newsletters and church bulletins. Participant recruitment will be self-referral with the participant making the first contact via telephone or e-mail with the researcher. Snowball sampling is also anticipated. The recruitment flyer will be posted at various community centers, senior citizens centers, and churches from a south Florida urban community, after permission is granted. The recruitment flyer contains brief information about criteria for consideration. The recruitment contains "tear offs," with the researcher's email address, and telephone number. Once the participant contacts the researcher, the researcher will arrange for a mutually agreeable time and place for the first interview to take place. The participant will select a pseudonym that will be listed on the demographic data form. The researcher will evaluate which participants fit the inclusion criteria during the initial phone call and again at the beginning of the interview. At the time of the initial phone contact, the researchers will clarify any questions the potential participant may have. During the first meeting, questions will be answered again, the participant will read and sign the consent form, and a consent form will be given to the participant at this time. The one-on-one, face-to-face, audiotaped, interviews lasting about one hour per session will be conducted by the researcher. Data collected from the interview will be transcribed by a transcriptionist (See Appendix E for form) following the first interview that will last no more than 1 hour; the participant will be given a $20 gift certificate in appreciation for their time. If agreeable, at the end of the first interview, the participant will be invited to review transcribed materials during a follow up interview. With participants that agree, arrangements will be made to hand deliver the transcription or send by mail or e-mail. Two weeks after the participant receives the transcribed material, the researcher will call the participant to arrange a follow-up meeting, with the time, date, and location agreeable to both parties. It is expected that the follow-up meeting will last about 15-30 minutes.

The one to one interviews will continue until data saturation occurs which means the researcher is confident that no other new information will be gained from additional interviews. The researcher will use a beginning opening question (See Appendix F and Chapter Three) after the demographic data is obtained and after the referral sheet is received. Other possible questions are included to prompt answers about the participants perceptions related to Advance Directives and end-of-life care (see Appendix K labeled interview guide).

4. Alternative Procedures

If an individual refuses to be audiotaped, the participant will not be enrolled. In addition, the participant may begin the study and not complete the interview. There will be no adverse effects for the participant for withdrawal. The research also has the right to stop the interview at any time. Additionally, if for whatever reason a participant drops out, or chooses not to divulge, information the participant will be excluded and another participant will be selected. The researcher will use two audiotape devices.

The researcher will keep a journal and take field notes to supplement the data following the interviews. The information that the participant who drops out provided will not be used in the analysis of the data, but the dropout rate may be referred to in scientific publication.

5. Benefits

There are no direct benefits from participation. However, an indirect benefit may be that the participant has the opportunity to discuss end of life concerns and their perceptions may ultimately assist health professionals to improve end of life care planning. At the end of the one-to-one hour-long interview, a $20 gift certificate will be given to participants as appreciation of their time to participants. A long-term benefit to society may be that information uncovered may help reduce health disparities of the elderly Black American population in a south Florida community.

6. Risks

There are no anticipated risks to participants. However, the associated risks of involvement could include emotions and anxieties involved with the acknowledgement of facing the inevitability of death, such as:

- Purposefulness and meaning of death
- Evaluation of death
- Lack of understanding
- Painful, possibly suffering associated with death
- Causation and illness associated with death

The following procedures will be used to minimize these risks:

- The researcher will provide referral information of persons and community agencies at the first interview meeting for support (see Appendix L labeled “Support Information for Participants”).

6. Anonymity

This is a confidential study. The information provided will be held in confidence to the extent permitted by law. Any published results of the research will refer to group averages only. No names or other identifying information will be used in reference to the

study. A self-assigned pseudonym will be used to refer to the participant in reporting the findings of the study. Data will be stored in a locked file safe in the researcher's home-

office. The signed consent form will be kept separate from the data collected by the interview, transcribed material, and/or field notes.

8. Consent

A copy of the consent form to be signed by the participants is attached. A copy of the consent form will give to each participant.

9. Certification

I certify that the protocol and method of obtaining informed consent as approved by the Institutional Review Board (IRB) will be followed during the period covered by this research project. Any future changes will be submitted to IRB review and approval prior to implementation. I will prepare a summary of the project results annually, to include identification of adverse effects occurring to human participants in this study.

______________________________ ____________________

Principal Investigator *Date*

*****Reminder*: Be sure to submit thirteen (17) copies of this form with your application.

APPENDIX E

TRANSCRIPTION CONFIDENTIALITY AGREEMENT

I________________________ agree to transcribe the audio tape recordings of the research "Perceptions of elderly Black Americans about Advance Directives." [redacted] are conducting the research. I understand that I will have access to confidential information about the study participants. By signing this statement, I am indicating my understanding of my obligation to maintain confidentiality and agree to the following:

- I understand that the names and any other identifying information about the participant are completely confidential.
- I agree not to divulge, publish, or otherwise make known to unauthorized persons or to the public any information obtained in the course of this research study that could identify the persons that participated in this study.
- I understand that all information about study participants obtained or accessed by me in the course of my work is confidential. I agree not to divulge or otherwise make known to unauthorized persons any of this information unless specifically authorized to do so by office protocol or a supervisor acting in response to applicable protocol, or court order, or public health or clinical need.
- I understand that I am not to read information and records concerning study participants, or any other confidential documents, nor to ask questions of participants for my own personal information but only to the extent and for performing my assigned duties on this research project.
- I understand that a breach of confidentiality may be grounds for disciplinary action, and may include termination of my contract between the researcher,
- [redacted].

- I agree to notify the researcher [redacted] Institutional Review Board Officer, (305) 899-3020 immediately if I become aware of an actual breach of confidentiality or situation which could potentially
- Result in a breach, whether this is on my part or on the part of another person.

__________________________ _____________ ___________

Transcriptionist Signature Date Printed Name

___________________________ _____________ ______________

Witness Signature Date Printed Name

APPENDIX F

RESEARCH QUESTIONS

1. What are your feelings about end-of-life care?
2. Tell me what you know about end-of-life care planning?

   if no proceed.
3. Can you tell me about any experience, if you have any, a close relative or loved one who died in the hospital? If yes, go to 3a, if no go to 3b.
4. Tell me about the end-of-life care that your loved one received as the time grew closer to their “passing?
5. Have you made any plans for your end-of-life care when it is your time to go?

APPENDIX G

RECRUITMENT FACILITY INITIAL CONTACT LETTER

[redacted]

«First_Name»

«First_Name»«Last_Name», «Title»
«Address_Line_1»
«City», «State»«ZIP_Code»
«Work_Phone»
«Email_Address»

«GreetingLine»

My name is [redacted]. I am a PhD candidate student, at Barry University, College of Health Sciences, Division of Nursing, and Miami Shores, Florida. I am writing to request your permission to explain my research project, “The Perceptions of Elderly Black Americans about Advance Directives.” I need your assistance in posting information about my project. The aim of this intended research may aid nurses in the preplanned end-of-life care of elderly Black Americans. I expect that the information acquired may help promote end-of-life planning among elder Black Americans.

I need your permission to post a flyer on bulletin boards, in newsletters, or in bulletins. I will not contact potential participants but expect them to call me if they are interested in this research. Posting flyers in appropriate locations or publications will provide your members an opportunity to volunteer as participants in this study.

I would like to request a few minutes of your time that I answer your questions about my research and bring you the flyer I have prepared. I will call you to schedule an appointment. Thank you for your time and ongoing community involvement.

Respectfully submitted,

[redacted]

APPENDIX H

RECRUITMENT FACILITIES

Greg Warner, Executive Director
Tamarac Senior Center
7501 N. University Dr.
Tamarac, FL 33321
954-724-2445
www.seniorsummit.org

Greg Warner, Executive Director
Tamarac Community Center
8601 W. Commercial Way
Tamarac, FL 33321
(954) 597-3620

Donna DeFronzo, Executive Director
N.E. Focal Point
Senior Center
227 NW 2nd St.
Deerfield Beach, FL 33441
(954) 480-4449
http://fl-deerfieldbeach2.civicplus.com/index.asp?NID=40

Poitier-Williams Senior Center
2815 NW 19th Street
Ft. Lauderdale, FL 33311
Phone: (954) 714-3500

Sandra Hunter, Project Director
Sylvia L. Poitier & Theodora S. Williams Senior Center.
2185 NW 19th St.
Ft. Lauderdale, FL 33311.
(954) 714-3500
www.seniorsummit.org.hunters@elderaffairs.org.
www.flhsmv.gov/ddl/vision/seniorcenters.html

Rosemarie Marco, Director
Sunrise Senior Center
10650 W Oakland Park Blvd
Sunrise, FL 33351
TEL (954) 746-3670

Treasa Brown, Executive Director

Lauderdale Lakes Senior Center4340 NW 36th St, Lauderdale Lakes, FL 33319

Phone: 9954) 535-2800, ext: 10
FAX: (954) 777-3249

Daphne Brown, Executive Director
Lauderhill Senior Center
1176 NW 42nd Way
Lauderhill, FL 33313
(954) 321-2450

Sandra Hunter, Project Director
North West Federated Woman's
Senior & Adult Care Center
2185 NW 19th St.
Ft. Lauderdale, FL 33311
954-714-3500

Yrrel Brinson, Community Outreach Coordinator
Redeeming Word Christian Center
2800 W Prospect Rd
Ft. Lauderdale, FL 33309
Phone: (954) 485-4933
http://www.rwcci.org/RWCCI/index.php

Coleen Chin
The Faith Center Ministries
5555 NW 95th Ave
Sunrise, FL 33351
(954) 742-7832
(954) 742-7776 Fax
http://www.thefaithcenterint.org

Sarina DiBari, Community Outreach Coordinator
Hospice by the Sea
Opening Doors" End-of-life Issues of African Americans
1531 W Palmetto Park Rd
Boca Raton, FL 33486
(561) 395-5031 (561) 393-7137
http://www.hospicebytheseafl.org/html/contactus.htm

The Salvation Army
1445 W Broward Blvd
Ft. Lauderdale, FL 33312 Phone: (954) 524-6991

APPENDIX I

Recruitment Flyer

Are You 65 Years or Older And A Black American?

If You answered **YES** to these questions, your participation Is **NEEDED** for a research study. I am a student at Barry University. I will be conducting research on:

"Perceptions of Elderly Black Americans About Advance Directives" (preplanned end-of-life care)"

If you would be interested in participating in this research, **PLEASE** contact me for more information. The researcher will ask participants about end-of-life care planning. Participation is **LIMITED** to the first eligible 20 individuals that qualify, and the study will be closed after that. If you qualify, your committed time will be no longer than one hour for an interview. You will be invited to participate in an optional second 15-30 minute interview to confirm contents of the first interview. The second session is not required.

Barry University
Division of Nursing
11300 Northeast Second Ave.
Miami Shores, FL. 33161-6695

CONTACT:

[redacted]

Or
SUPERVISOR:

[redacted]

and

[redacted]

[redacted]

APPENDIX J

DEMOGRAPHIC QUESTIONNAIRE

To be completed by the researcher, by telephone, after potential participant contact (The assignment of a number and False Name CANNOT be connected to you in any way; it is used for statistical information only)

PARTICIPANT#	Pseudonym (Fake Name	DATE	
ADVANCE DIRECTIVES	YES	NO	
BLACK AMERICAN	YES	NO	
AGE			
SEX	FEMALE	MALE	
MARITAL STATUS	MARRIED	WIDOWED	OTHER
ARE YOU RESPONSIBLE TO TAKE CARE OF ANYONE ELSE	YES	NO	OTHER
MEDICAL INSURANCE RELIGIOUSPREFERENCE	PRIVATE	MEDICARE	OTHER

DO YOU <u>OR</u> SOMEONE ELSE MAKE MAJPOR MEDICAL DECIONS ABOUT YOUR HEALTH	YES	NO,	IF NO WHO?
ARE YOU EMPLOYED	YES	NO	
ANNUAL INCOME	$0-12,000	$13,000-50,000	$50,000+
LEVEL OF EDUCATION	LESS THAN 12	GRADUATED HIGH SCHOOL	COLLEGE

** If you want the results from this study PLEASE give your name and address to the research assistant.

APPENDIX K

INTERVIEW GUIDE

RESERCHER: Hello, my name is [redacted]; I am the researcher here for our scheduled interview. Before we begin, I would like to give you some information on referral agencies should you have any concerns (see Appendix Labeled "Support Information for Participant").

*Thank the participant for volunteering for the study and no ill effects will come to them for "dropping out" explains to them why they are not appropriate for the study. Refer them back to the packet of information they were given at the introduction. Allow them to express their feelings about the experience. Refer them to [redacted] [redacted] Included in the packet, given to them at the beginning of the Interaction; for any concerns about the nature of the intended research, or other concerns that they did not feel comfortable discussing with the researcher. Last, bid them goodbye.

**The researcher will verify, with the participant, the
Information provided on the demographic questionnaire (Appendix J),
and the consent are accurate and reinstate to the
Participants that:

- Their participation is strictly voluntary
- They can discontinuance participation for any reason, at any time. The researcher does not have to be provided a reason
- Restate the benefits of participation
- Terms of $20.00 participation as a token of appreciation

APPENDIX L

SUPPORT INFORMATION FOR PARTICIPANTS

BROWARD COUNTY HEALTHCARE SERVICES DIVISION
Administration
115 S Andrews Ave., Room 318, Ft. Lauderdale, FL 33301
GENERAL INFORMATION: 954-357-5444
FAX: (954) 357-5468
Hearing Impaired / TTY (954) 537-2882

Residential Services:
Licensed Clinical Psychologist: 954-341-3925

Outpatient Services:
Licensed Clinical Psychologist: 954-831-156

Outpatient Satellite Offices
Carver Ranches Multi-Purpose Center - PAP 954-985-1920
4733 SW 18th Street, Hollywood, FL 33023

Hepburn Multi-Purpose Center 954-457-1703
750 NW 9th Avenue, Hallandale, FL 33009

Financial Services and Support Staff 954-357-5444
115 S. Andrews Ave. , Room 318,
Ft. Lauderdale, FL 33301
FAX 954-357-5469
Administrative Manager: 954-357-5450

Primary Healthcare 954-327-8750
Mental Health Section 954-327-8750

VITA

DALE E. FLENYOL, MS, CRNA
[redacted]
E-mail: dale.flenyol@mymail.barry.edu

Florida Department Health: ARNP [redacted]

American Association of Certified Nurse Anesthetists: CCRN #: [redacted]

BACKGROUND

[redacted]	Born – Brooklyn, NY

EDUCATION

1977- 1979	A.D.N., Nursing Forsyth Technical College Winston-Salem, NC
1981-1987	A.S., A.D., Biology Richland Community College Decatur, IL
1989-1991	B.S., Nursing, Florida International University Miami, FL
1992-1995	M.S., Anesthesiology Barry University Miami Shores, FL
2001-Present	PhD, Nursing Barry University Miami Shores, FL

2012- Present	CRNA Certified Registered Nurse Anesthetists Independent Contractor, Lauderhill, FL
1996- 2011	CRNA, Clinical Coordinator Student Nurse Anesthetists Sheridan Healthcorp, Inc. Sunrise, FL
1995-1996 J.F.K. Medical Center	Certified Registered Nurse Anesthetist Lake Worth, FL
1979-1989	Staff Nurse, RN North Broward Med Center Ft. Lauderdale. FL
1979-1981	Staff Nurse NC Baptist Hospitals Winston-Salem, NC