

African American Seniors' Perspectives on Advance Care Planning:
A Virtue Ethics Community-Based Participatory Research Approach

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Sandra Kaye Crump, RN, MSN

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Ruth Lindquist, PhD, RN, ACNS-BC, FAAN

Professor, Adviser

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Dedication

To my son, Cedric, this concludes about 40 years since I began my college career. Be patient but persistent. Relax and enjoy the learning, the degrees will come.

To my niece, Valecia, I hope that this provides you with the impetus needed to finish your PhD.

To the many brilliant African-Americans who have never considered pursuing graduate education because they didn't think that it was important or that they could do it, this is for you. It is important, it can be done, you are needed, and it is never too late to begin.

To the many African-Americans students who are currently pursuing degrees and feeling discouraged, I encourage you to be clear about your motives and true to yourself. Don't be dissuaded by challenges to your truth, if you believe it, fight for it.

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Abstract

Some findings not previously noted in the literature were found in this research. African-Americans are far less likely to write advance directives than white Americans but little is known about African-Americans' perceptions of planning for who would speak for them if they were unable to speak in critical health situations. Health professionals' lack of knowledge about culture, ethnicity and/or religion is an obstacle to effective end-of-life care. This research is aimed at exploring African-American seniors' perspectives and providing health professionals with information to build skills to support ethnically diverse families of patients who are seriously ill and unable to speak.

A community-based participatory research (with focus groups) approach was used to produce knowledge with participants from one Midwestern urban community. A community advisory board was active in all aspects of the research. A virtue ethics framework was used to maintain the integrity of the research. The history and ethics of conducting research is reviewed. Forty-five female and 7 male African-American seniors (aged 59-92) participated in the nine, one time, focus groups.

A PowerPoint about advance care planning and a questionnaire (based on the literature) were used to stimulate thought prior to focus group discussions. Data revealed 30 themes which were divided into five primary categories: Trust, fear, relationships, lack of information/knowledge, and procrastination; and six secondary categories: Deracination (cultural uprooting), deterioration of family/community, past discrimination, experience, self-fulfilling prophecy, and religion. Study participants expressed that African-Americans distrust the dominant society and their families; and

have a general fear of death and dying. They connected deterioration of the African-American community and family to ongoing discrimination and racism and cited this as contributing to the reluctance to write advance directives. Another major finding is that choosing a proxy decision-maker requires “analyzing personal relationships” and this can be painful and cause avoidance of addressing advance care planning. This had not been previously identified in the literature.

Recommendations are that healthcare providers treat African-American seniors with respect, and get to know them socially so they aren't uncomfortable and afraid around them. Participants suggested patients connect with providers and share their goals for health and personal life; and that providers have more information about advance care planning in their curriculum and training. The researcher recommends providers use clinical opportunities to identify situations where they could empower patients to take charge of their advance care planning; and community members should identify their personal value system, and think about quality of life issues. Community education programs by a trusted professional are recommended to give African-American seniors information needed to understand the importance and urgency of advance care planning. Assistance of a skilled professional to assist with difficult decision-making and planning is also needed.

Further research is needed to better understand how the African-American historical experience in the United States contributes to their reluctance to engage in advance care planning. Further research is also needed to find the social and economic value and the political implications of advance directives.

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Chapter 1: Introduction

Over the past 25 years, this researcher has questioned how people make decisions about their healthcare. Of particular interest was how seniors make decisions in anticipation of the end of their lives, or setting in place a plan for who would speak for them if they should become sick and unable to speak for themselves regarding treatments, and aggressiveness of their care. For one subgroup of this population, African-American seniors, relatively little is known regarding this latter issue. This group is of particular interest due to their historical treatment dating back to times of slavery and its aftermath, and considering that Caucasians are the dominant group providing healthcare and establishing treatment and non-treatment decisions. The memories and meaning of history and the past may be particularly salient to seniors, who are also most likely to become seriously ill or die as they advance in age. This research project is aimed at gaining insight and understanding of the perspective of African-American community dwelling seniors about who would speak for them if they were very sick and unable to speak for themselves. To that end, the research explores African-American seniors' views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives. More specifically the research aimed to elicit the perspectives of these seniors about decision making related to executing a living will (LW), durable power of attorney for health care (DPOA-HC or DPA-HC), or naming a healthcare proxy or surrogate decision maker.

Research comparing African-Americans to whites is reviewed, but it is not the intention of this research to make comparisons of the decision making of African-

Americans to whites. The comparisons are made only to show the differences in the statistics. The literature review was aimed at uncovering what is known about African-American seniors' perspectives on advance care planning and writing advance directives. This research utilized a community-based participatory research (CBPR) methodology with focus groups to produce knowledge regarding the perspective of African-American community-dwelling seniors in one Midwestern urban area about who would speak for them if they were very sick and unable to speak for themselves. CBPR is a type of research that is formulated and conducted in context of an equal partnership between the scientific-oriented "experts" (researchers) and the real-world existential "experts" (members of a community). In CBPR projects, the community participates fully in all aspects of the research process along with the investigator. It was believed that the use of such methods within this cultural community would better fit the cultural mores of the community and in so doing, would honor the traditions, history and sensitivities of the cultural group. It is likely that if a community is fully engaged in a research study, it would result in findings that are more "true" to the reality of their existence; and/or, that the answer to the research question would be more completely provided. It was also believed that the conduct of CBPR to gain insight and information regarding the perspective of African-American community dwelling seniors about this topic was the most ethical approach.

This researcher has recently replicated a national survey of critical care nurses at a local Midwestern medical center to assess their perceptions of obstacles, supports and knowledge needed to provide quality end-of-life care (Crump, Schaffer, & Schulte,

2010). The findings of this replicated study, as well as the original national study (Beckstrand & Kirchhoff, 2005), revealed that many of the issues most perceived as obstacles could potentially be reduced if the patients had *ideally* completed advance directives. *Ideally* means that the advance directive is completed with the individual, a qualified professional, and the patient's family and/or member(s) of one's desired kinship network prior to a hospital admission (i.e., when the individual is still a community dweller) (Crump et al., 2010). Advanced directives and advance care planning are the vehicles to set in place a formal plan regarding who would speak for you if you were facing serious illness and could not speak for yourself. Such a plan is designed to ensure that one's wishes for treatment and care are respected.

Attitudes about Advance Care Planning

Americans, in general, tend to be reluctant to talk about death. Death is often referenced with a war or battle metaphor, to be "fought" with every possible resource. In American culture, illness and death are highly "medicalized" in that care of the seriously ill or dying is frequently removed from the home and it takes place in a hospital or a foreign or unfamiliar environment with healthcare providers who may also be unfamiliar. In such an environment, one's preferences for treatment and care may not be known nor even solicited. To compound the complexity of such situations, African-Americans tend to believe that they will not receive the same amount and quality of healthcare as white Americans, and are less likely to trust healthcare providers in end-of-life situations (Bullock, McGraw, Blank, & Bradley, 2005; Schaffer & Norlander, 2009, p. 161; Waters, 2001).

Most data regarding African-American's attitudes about advance directives indicate that African-Americans do share some of their thoughts about their wishes for end-of-life care with family and friends but tend to be reluctant to put such thoughts in writing. This is thought to be primarily due to cultural discomforts, lack of trust, and fear that it might work to their detriment (Baker, 2002; Caralis, Davis, Wright, & Marcial, 1993; Dupree, 2000; Waters, 2001). African-Americans and other people of color are also believed to be more likely than white Americans to consider extended family and friends in a way that does not fit the profile for legal next-of-kin (Dennis & Neese, 2000; Waters, 2001). These relationships (referred to as kinship networks in this research) can cause significant problems for health professionals needing to share information and make decisions about patients within the current laws for privacy and confidentiality.

The lack of adequate knowledge about culture, race, ethnicity and/or religion is perceived as an obstacle to effective end-of-life care by critical care nurses (Beckstrand & Kirchoff, 2005; Crump et al., 2010). Increased knowledge of culture and ethics were also identified as major needs of nurses (Bullock et al., 2005). Providing nurses and other healthcare professionals with knowledge and skills to build relationships across cultural differences and to understand some of the ethical concerns could increase their ability to support ethnically diverse families whose loved one is seriously ill and unable to speak and/or having an end-of-life experience (Crump et al., 2010). This requires healthcare professionals to be informed regarding the perspectives of the communities and community members for whom they care regarding end-of-life and preferences for treatment and care. Study of the perspectives of cultural communities that focus on these

issues may provide information that can enable culturally sensitive care to improve the experience of serious illness and end-of-life care for diverse populations.

In the conduct of such studies with culturally diverse communities, the researchers must be scrupulous in their ethics, thoughtful in their approach, and sensitive in their methods and manners to gain the trust of the community participants. To this end, this researcher, who is an African-American, has been connecting with African-American seniors in the community selected for this research for approximately three years, and has earned their trust and support. The researcher has identified seniors from the community to serve as the community advisory board for the present project to further assure sensitivity and wisdom in the approach to the research in the community with community members, and to provide ongoing guidance in the conduct of the research; such partnership is recommended to maintain integrity of the work and its findings (Dresden, McElmurry, & McCreary, 2003).

Maintaining the integrity of research also necessitates that ethical principles be identified and adhered to. Thus, a virtue ethics framework entitled “A Virtue Ethics Guide to Best Practices for Community-Based Participatory Research” (Schaffer, 2009) was identified to guide the researcher in the work. Hearing the voice of seniors of an African-American community through the use of focus groups; engaging the community in the conduct of CBPR; working closely with the Community Advisory Board; and tightly adhering to the principles of virtue ethics; were foundational to the conduct of the present research.

Purpose of the Research

The primary purpose of this project was to explore African-American seniors' (aged 60 years and older) views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives. A secondary purpose was to explore the use of a virtue ethics framework in the approach to address the research question. It was believed that such a model would render the work more culturally sensitive. It was also believed that the successful application of such a model could result in the identification of a helpful model for others who are conducting CBPR. This research could serve to highlight the importance of this approach. It is hoped that the findings of this research can be used to identify and develop methods or approaches to help nurses and other health professionals to gain skill and understanding of ethical and cultural concerns when addressing advance care planning and writing advance directives with African-American seniors.

In the next chapter, background regarding the history and research ethics of concern to the African-American community, a review of literature focused on advance directives and what is currently known regarding perspectives about advance directives among African-American communities, the conceptual framework, and specific aims are presented.

Chapter 2: Background and Review of Literature

Overview

This chapter provides an overview of literature contributing to current knowledge of advance care planning with African-American seniors. The background perspectives are foundational and therefore define the research and review. Advance care planning consists of thinking about cares one would want if very ill and unable to speak; then executing an advance directive, which consists of a living will (LW) and/or a durable power of attorney for health care (DPOA-HC). Advance care planning is more than the sum of its parts; it is a complex, experiential issue. The background of this chapter flows into the review of the literature. The review was designed to determine what the existing published literature reflects regarding this complex, multidimensional issue that affects African-American seniors' decision to engage in discussions about advance care planning and writing advance directives.

The review aims to determine how African-American seniors' wishes concerning treatment and care are communicated, and their attitudes toward writing advance directives. It also aims to identify what is currently known and understood about the very complex issues affecting African-American seniors' views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives. More specifically, this review aims to gain insight and understanding of what is known of the perspectives of African-American seniors about who would speak for them if they were very sick and unable to speak for themselves.

First, the chapter outlines the case and legal history undergirding current research ethics. Then, research and medical paradigms that underpin this research are reviewed. Following the paradigms, an overview of advance care planning is laid out along with high profile legal cases that challenged our society to take a legal stand regarding advance planning. That is followed by a critical review, synthesis, and summary of the literature. The literature review is summarized, and gaps in knowledge are identified. The chapter concludes with a restatement of the study purpose and the research question is addressed.

Background – Precedents and Historical Cases

It is important to review a number of precedents and historical cases to track the progression of events leading to the development of our current laws and ethical perspectives on research with human subjects relevant to the present project. The Tuskegee Syphilis Study, conducted from 1932-1972, was a significant event in that history and it is described here in detail. The researcher believes that the Tuskegee Syphilis Study could not have happened were it not for the African-American nurse, Eunice Rivers (Rivers, Schuman, Simpson, & Olansky, 1953). A detailed section on Nurse Rivers outlines how she encouraged the men to remain in the study. The Tuskegee Study and Nurse Rivers are described in detail because in its aftermath one can understand how an African-American nurse can be viewed with more suspicion than an outsider with this population. It is also why the minority nurse researcher must endeavor to avoid the pitfalls of the Tuskegee nurse. Much of the literature points to the highly publicized, infamous Tuskegee study as a primary reason for the mistrust, actually

distrust, African-Americans have towards the healthcare system and their reluctance to participate in research. Harriet Washington (2006) details numerous other cases in her book, “Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present.” This section outlines the history of the ethics of research related to this project.

History of the ethics of research. There are a number of contributors to the history of research ethics in the United States that led to the establishment of the current Institutional Review Board (IRB) (Amdur & Bankert, 2007). Institutional review boards were established under the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (NCPHSBBR) which met from 1974-1978. The Belmont Report, which was submitted by the NCPHSBBR in 1978, sets forth the basic principles of acceptable conduct when conducting research with humans in the United States. The basic regulations are in the Code of Federal Regulations, Title 45, Part 46 in 1981 and after several revisions became the IRB as we know it in 1991 (Health & Human Services, 1993). The IRB “...is an administrative body established to protect the rights and welfare of human research subjects recruited to participate in research activities conducted under the auspices of the institution...” (Health and Human Services, 1993, ch1, p. 1.). Institutional review boards are mandated to provide oversight and review authority in the conduct of all research which is subject to the authority of the Department of Health and Human Services and the Food and Drug Administration (Amdur & Bankert, 2007, p. 6). Mandated oversight was instituted because of atrocities that occurred, throughout the world and in the United States, to persons and populations

in the name of science (Amdur & Bankert, 2007, pp. 7-19). High profile examples of such atrocities are referenced below.

The Nuremberg War Crimes Trials examined the conduction of biomedical experiments on concentration camp prisoners. These trials led to the development of the 1946 Nuremberg Code which became the prototype for ethical treatment of human subjects in research (National Institute of Health, Office of Human Subjects Research, 1949). The Tuskegee Syphilis Study, conducted by the United States Public Health Service (USPHS) began in Tuskegee, Alabama in 1932. When the Tuskegee Syphilis research began, guidelines for ethical treatment of research subjects had not been established. However, Alabama did have a venereal disease law in 1927, which required the reporting and treatment of many venereal diseases including syphilis. The 1972 exposure of the atrocities of the Tuskegee Syphilis Study (among other research concerns of the time) and its subsequent investigation led to the establishment of Public Law 93-348, the National Research Act and the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (NCPHSBBR) in 1974. This Commission was established to develop ethical guidelines for research involving human subjects in the United States. After several years of data collection and deliberations, on April 18, 1979 the resulting Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979) was released. The Belmont Report established boundaries between research and practice as well as basic ethical principles for conducting research on humans. The following is a brief discussion of that process.

Belmont report. The basic ethical principles of respect for persons, beneficence and justice are generally accepted as relevant in United States culture. Respect for persons requires respecting decisions of people capable of deliberation, and protecting those with diminished capacity, to decide. Beneficence requires that risks and benefits of harm be assessed in systematic ways, and interventions be administered so as to minimize harm and maximize benefits. Justice requires that there be fair distribution of selection of research subjects so as to avoid selection of vulnerable populations. These ethical principles led to the development of informed consents, which requires subjects/patients to have all relevant information, comprehension of the information, and the right to choose what shall happen to their person, which is voluntariness (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

The Tuskegee syphilis study. The Tuskegee Syphilis Study was the U. S. Public Health Service's "Study of Syphilis in the Untreated Negro Male." It was conducted with poor, uneducated sharecroppers who lived in rural Macon County, Alabama. This study has been called the most unethical research on humans conducted in United States history and, lasting for forty years (1932 – 1972), it is the longest non-therapeutic "experiment" conducted on humans in the world (Jones, 1993). In this study, 399 African-American men with latent syphilis were told that they were receiving treatments for syphilis when they received blood draws, spinal taps and other examinations. However, even after penicillin was identified as a safe and effective cure for syphilis, treatment was withheld from the men so that the effects of untreated syphilis could be studied through their death.

The Tuskegee Syphilis Study is particularly concerning for the prospective subjects chosen for the present research because they were born before 1950 and most are probably familiar with this study or its effects. While this is the most well-known incidence of unethical medical experimentation on black Americans, Harriet Washington (2006) gives a detailed history of the many reasons black Americans are, and should be, reluctant to participate in research. One of the most oft-associated members of the research team of the Tuskegee Study was Nurse Rivers, who recruited and maintained the involvement of the participants to their detriment and death. She was viewed as having particular salience to the present research by the fact that the present researcher is also a female African-American nurse.

Nurse Rivers. Miss Rivers was the daughter of a farmer who was born in Georgia and lived in the Tuskegee area all of her life. She graduated from Tuskegee Institute School of Nursing in 1922 and was one of only four black public health nurses in the state of Alabama. She worked in various community health nursing and public health statistics positions for eight years. She was a night supervisor of the John Andrew Memorial Hospital in Tuskegee for two years before being offered a position as supervisor of a New York hospital in 1932. Miss Rivers turned down the New York job to stay in Alabama as a “scientific assistant” with the Untreated Syphilis in the Negro Male Study (more commonly called the Tuskegee Syphilis Study) of the Division of Venereal Disease of the U. S. Public Health Service.

Miss Rivers’ job was to assist with procedures and examinations and to keep track of the men in the Tuskegee Syphilis Study so that autopsies could be performed when

they died. She used her familiarity with the community, its customs and culture, and her skills as a public health nurse along with a few tonics and vitamins to make the men believe they were receiving treatment for their *bad blood*. Bad blood was a euphemism for numerous diseases from anemia to leukemia and included syphilis. Miss Rivers further gained the trust of the men by providing hot lunches and allowing them to stop and visit with their friends as she transported them to the clinic. These trips to the clinic were a way for the men to get away from the drudgery of their everyday lives.

Miss Rivers listened to the men's complaints about the doctors and intervened on their behalf if the doctors were brusque with them. They were part of *Miss River's Lodge* and she treated them like they were "important government patients," which is what they were told they were. She explained procedures such as spinal taps and blood draws as treatments that would help them. Despite the fact that most of the men and their families did not believe in autopsy, Miss Rivers convinced the men to have the autopsies in exchange for free burials. She did not tell the men that they had syphilis or that they should get the essentially safe and effective penicillin when it became available in 1943. In fact, the men were discouraged from getting treatment. The HBO movie *Miss Evers' Boys* is an excellent depiction of Miss Rivers' role in the Tuskegee Syphilis Study (Sargent, 2001).

Miss Rivers' claim is that she believed that rural areas needed good, sympathetic nurses to contribute to, and carry out, effective public health programs to improve health and advances in public health (Rivers et al., 1953). She was a Negro nurse who was working in an environment where she had autonomy in her nursing practice and was

respected for her skills, at a time when nurses were handmaidens to doctors. The present researcher feels certain that Miss Rivers was aware of the ethical discussions that began with the Nuremberg Trials, and the recommendations of the Judicial Council of the American Medical Association in 1946. In the supplementary report of the Judicial Council the proposed requirements were:

(1) the voluntary consent of the person on whom the experiment is to be performed must be obtained; (2) the danger of each experiment must be previously investigated by animal experimentation; and (3) the experiment must be performed under proper medical protection and management (Supplementary Report... JAMA, 1946 132; (17), p. 1090).

However, even after the ethical question was openly raised in 1965, Miss Rivers still failed to act or to remove herself from the study (Washington, 2006, p. 176). The present researcher believes that Nurse Rivers cannot be held totally liable for the study itself, given the historical context in which this atrocity took place, but she cannot be allowed to totally escape blame. Regardless of the placement of blame, the impact of this historical study is still alive in the minds and affecting the trust of potential African-American subjects today.

Recruiting African-American seniors for research. African-Americans in general are reluctant to participate in research, presumably because of the overall experience of the African-American in the United States. Harriet Washington (2006) outlines countless reasons for this reluctance in her book “Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the

Present.” It was anticipated that it would be especially difficult to recruit African-American seniors for the present research because of the subject matter, which includes death; dying and facing issues of one’s own demise. The discussion of Nurse Rivers is important because it gives voice to the kinds of concerns anticipated when recruiting for research from this population. African-Americans tend to believe that white researchers do not care about them, cannot be trusted and (if at all) they would prefer a black researcher (Waters, 2001). However, differences in the status of the black researcher and the general African-American community can exist (Dennis & Neese, 2000) and be problematic. It would have required tremendous moral courage for Miss Rivers to expose or remove herself from the Tuskegee study but the researcher believes that nurses, and particularly minority nurses, must insure that they do not act as conduits to racist, unethical or unprofessional treatment of patients in any setting. When conducting research with minority communities, the nurse researcher must endeavor to never become the Tuskegee nurse. To this end, this researcher, who is an African-American nurse, has been connecting with African-American seniors in this community for approximately three years and has worked to earn their trust and support. The researcher has found seniors from the community to serve as a community advisory board to provide guidance in conducting this research (Dresden et al., 2003). The use of a virtue ethics framework as an approach to conducting research in the African-American community is also aimed at addressing this issue. Details of the recruitment process and the study’s community advisory board are located in the methodology section of this paper. The next section outlines other historical events that laid the groundwork for the present study.

Establishment of patient self determination act. The Patient Self Determination Act (PSDA) (1990) requires that all patients who are admitted to hospitals, nursing facilities, home health care, hospice programs and health maintenance organizations receiving Medicare funds be presented with the “opportunity” to write an advance directive (Baker, 2002; Caralis et al., 1993; Library of Congress THOMAS, 1990). The PSDA is a subpart of P.L. 101–508, (104 Stat. 143), Omnibus Budget Reconciliation Act of 1990, which had the primary objective of reducing Medicare costs. However, very few advance directives are completed in in-patient settings, and it appears that they should be written prior to an in-patient stay. The Office of the Inspector General recommended that the Health Care Financing Administration (HCFA), now called Center for Medicare and Medicaid Services (CMS), take the lead in developing a plan for educating the public on advance directives (Health and Human Services, Office of Inspector General, 1993). Advance care planning is recommended by most professional healthcare providers’ credentialing and accrediting organizations (Fagerlin, Ditto, Hawkins, Schneider, & Smucker, 2002); however, there is essentially no funding to assist individuals to complete advance care plans and very little support for education of professionals to acquire the information to assist patients. In fact, even though all healthcare organizations are required to provide information regarding advance directives, there are no codes to bill for this as a healthcare service. As of January, 2011 legislation to reimburse education programs, or assistance to complete advance directives has not been successful (Pear, 2011).

Other events and concomitant changes in the healthcare system and policy also contribute to the need to conduct the present work and the significance of the study. One of the events or trends in healthcare is the growing attention to healthcare [biomedical] ethics. Recent attention has been given to autonomy and privacy; guidelines for the use and dissemination of healthcare information; and advance directives and end-of-life decision-making. These are described below.

Autonomy and privacy. For many years, autonomy has been taken to be the prima facie principle in biomedical ethics, that is, it takes precedence over all other principles (Johnstone & Kanitsaki, 2009). In the newer edition of their book, Beauchamp and Childress (2001) deny that autonomy “overrides all other moral considerations” (Beauchamp & Childress, 2001, p. 57) as outlined in the chapter on “Respect for Autonomy” (Beauchamp & Childress, 2001, pp. 57-103). Autonomy and privacy are central principles underlying patient’s rights of self-determination. The Patient Self Determination Act provides for the “opportunity” for advance care planning and writing advance directives. However, to “require” the writing of an advance directive would be an invasion of the individual’s autonomy. Rules of privacy such as the Health Information Portability and Accountability Act (HIPAA) demand that communication of health information follow strict guidelines. If no written guidelines direct otherwise, information can only be shared with legal next of kin. African-Americans and other people of color are believed to be more likely than white Americans to consider extended family and friends in a way that does not fit the usual profile for legal next of kin (Dennis & Neese, 2000; Waters, 2001). Within the current laws for privacy and confidentiality,

these extended family relationships (referred to as kinship networks in this research) can cause significant problems for health professionals needing to share information and make decisions on behalf of patients.

Health information portability and accountability act (HIPAA). Autonomy and privacy principles guide the Health Information Portability and Accountability Act of 1996 (HIPAA) PL 104-91 (Health and Human Services, Office of Civil Rights, 2003). This law provides strict guidelines for the use and dissemination of healthcare information. The final Privacy Rule and Administrative Simplification Rules related to HIPAA were published on August 14, 2002. These rules apply to health plans, health care clearinghouses, and to any health care provider who transmits individually identifiable health information or protected health information. HIPAA rules can cause considerable conflict when patients are unable to speak for themselves, and the people they wish to have access to their protected health information are not their legal next of kin. HIPAA rules were loosely enforced for several years but since 2005 HIPAA violations have taken a zero tolerance stance in most institutions (McClendon, 2010).

End-of-life discussions with African-Americans. The literature reveals that it is culture or ethnicity that is the determining factor of whether African-Americans engage in advance care planning activities and write advance directives, not education, religiosity or income level (Baker, 2002). African-Americans tend to want more lifesaving care than white Americans at the end-of-life and are less likely to trust healthcare providers in end-of-life situations (Perkins, Geppert, Gonzales, Cortez, & Hazuda, 2002), but the reasons for these tendencies are not clear (Phipps et al., 2003). African-Americans also tend to

believe that they will not receive the same amount and quality of health care as white Americans, particularly if they put a preference for (less) care in writing (Bullock et al., 2005; Gerst & Burr, 2008; Schaffer & Norlander, 2009; Waters, 2001). Having discussions with African-American seniors about their views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives is a way to get at what it is about ethnicity that prevents them from engaging in end-of-life discussions and writing advance directives.

The following section will outline the philosophical grounding and paradigms examined to underpin this research. A medical paradigm and research paradigm is outlined.

Philosophical Grounding and Paradigms Examined

The philosophical foundation of the present work was established after a review of methodological approaches that could possibly address the stated research question. A number of relevant paradigms are reviewed to add contrast and clarity to the work. The selected paradigms are described below.

Philosophical grounding of research. Prior to beginning a research project, the researcher established a philosophical grounding. In his book, “Research is Ceremony: Indigenous Research Methods,” Shawn Wilson (2008) offers some useful definitions. Many of the concepts outlined in Wilson’s book provide clarity to the methodological approaches utilized in this research. They are briefly reviewed here.

Ontology is a theory of the nature of reality. Once a set of beliefs is established about what reality is, the research follows on faith to discover what is real. Epistemology

is the study of knowledge or thinking; how we know what we know. Epistemology (how we know) and ontology (what is real) are connected in that what one believes is real impacts what they perceive as knowledge about that reality; or, *how you know what is real*. Methodology is the theory of how knowledge is obtained. Ontology and epistemology directs the methodology.

What one perceives as reality (ontology) dictates how they perceive knowledge about that reality (epistemology) and therefore dictates the methods that are used to obtain new knowledge. Axiology is the morals and ethics that guide and judge the worthiness of particular research and dictates the methods used in pursuit of certain knowledge. Three “what” questions are important to ask about the proposed research: what is worth finding out more about; what is ethical to do to find it out; and what will you do with your findings (Wilson, 2008, p. 34)?

Wilson (2008) uses the term indigenous to “refer to the people or peoples who identify their ancestry with the original inhabitants of Australia, Canada and other countries worldwide” (p. 34). This term is relevant to this research because African-Americans are kept in *their place* by skin color. This skin color keeps them connected to their ancestral Africa just as white skin is connected to ancestral Europe. No matter whom they are or what they do, African-Americans are seen as belonging to their indigenous land first. This keeps African-Americans more closely connected to their indigenous cultural identity than to the dominant United States cultural identity. Wilson (2008, p. 35) defines dominant as the culture of European-descended and Eurocentric,

Christian, heterosexist male-dominated Canada or Australia; we can add the United States.

In the United States and nations around the world, the term “dominant,” like the culture it describes and the society it creates, has an inherent privilege or superior status. This *superiority* is not earned but is a matter of membership in the dominant society. To maintain this dominance or presumed superiority, it is incumbent on its members to exclude those who fall “outside” this powerful majority. People who are not men, heterosexual, physically or mentally perfect, white, or any other people who, for whatever reason, do not “fit in” the dominant culture are minorities and seen as having an inferior status. African-Americans fall outside the dominant culture and thus research for the benefit of improving their condition requires reconciliation of this issue.

In the following sections, medical and research paradigms are reviewed and the approach for the present study is identified.

Medical paradigms. Medical science has promoted a mechanistic vs. probabilistic paradigm over the past 120 years or so. Certainty is the cornerstone of the mechanistic paradigm in which a cause can, and should be found for any problem. In the mechanistic paradigm of healthcare, the cause of an illness must be found and every effort aimed at finding a cure. Certainty is based on scientific data and the notion of the subjective is viewed as irrational. This places cause and cure outside the control of the patient. According to this paradigm, if an illness is not cured, it is either because the correct cause and cure has not yet been found and/or the patient is non-compliant. Failure to obtain complete control and/or a cure in this paradigm is seen as a failure on the part of

the patient or the healthcare provider. The influence of the mechanistic paradigm has led us to expect certainty (Bursztajn, Feinbloom, Hamm, & Brodsky, 1990).

The probabilistic paradigm allows for more than one cause and acknowledges inherent uncertainty. In this paradigm, it is impossible to eliminate subjective knowledge from scientific inquiry and all knowledge is viewed on a continuum. Experimentation is principled gambling and cause and effect is subject to chance and change. The investigator chooses a hypothesis to believe in and whether or not the hypothesis turns out to be true or false constitutes a gamble. Winning and losing in the probabilistic paradigm is a matter of analyzing cost/risk v. benefit. How much can I afford to lose/risk? What do I stand to gain/win? What are the odds that one or the other will occur (Bursztajn et al., 1990)?

It takes but a brief overview of these paradigmatic approaches to medical science to see that they encompass two entirely different world views about what information is important and when, and if, a patient should have significant involvement in decision making. It is then but a short step to see that the healthcare provider, patients, and their kinship networks could view the world, and thus what is important, quite differently. When socio-cultural factors such as age, race, ethnicity, culture, education, religion, past experience with the healthcare system, access to health insurance, and income level are factored in, this gap can widen even more. For people operating out of the mechanistic paradigm, the lack of certainty inherent in the probabilistic paradigm may equate to chaos and make thinking probabilistically very difficult. However, it is important to understand that decisions *must* be made even though there is a degree of uncertainty about them. In

other words, one must make critical choices in the face of uncertainty (Bursztajn et al., 1990).

If one is grounded in the mechanistic paradigm, uncertainty leads to stress and anxiety. To avoid stress and anxiety, one may retreat to a false sense of certainty, go into a state of denial, or shift responsibility to someone with more power. People of faith will often “leave it up to God.” In the past, physicians have been anxious to assume the powerful paternalistic role of decision maker. Physicians want to do what is *best* for their patients and often exhibit excessive confidence in recommendations that have a high degree of uncertainty. Physicians’ perspectives and presentations of information can give patients a distorted view of options (Parascondola, Hawkins, & Danis, 2002). Even if options given are *medically best* for patients, they may not be inclusive of the patient’s values or respect their right to self-determination. Clinicians should disclose uncertainty and help patients decipher complex probabilities.

Physicians should have more ease in communicating uncertainty while maintaining the confidence and trust of the patient (Parascondola et al., 2002). Physicians seem to be reluctant to discuss complex issues around end-of-life with patients even when the patient has been hospitalized in an ICU (Crump et al., 2010). Patients expect that their physicians would initiate conversations about advance directives prior to a crisis situation (Caralis et al., 1993), but physicians remain reluctant to engage in this discussion (Caralis et al., 1993; Parascondola et al., 2002). Even when patients have already executed an advance directive, they are still likely to not have had discussions with their physician (Caralis et al., 1993).

The current mechanistic paradigm of medicine is ineffective as evidenced by increasing malpractice suits, trends toward alternative medicine, patients' rights movements, and growing healthcare costs (Bursztajn et al., 1990). Improved technology, chronic illness, diverse populations, and limited economic resources have led to the need for a more probabilistic view of healthcare. The public has come to expect that all possible technology will be used to obtain precise diagnoses and treatment options for any ailment. This use of technology has led to people living longer in chronic disease states, to the point of multi-organ failure, which is inevitable in old age. Death at any age or health status is seen as a failure of the current U. S. healthcare system. The majority of economic resources for health are still being spent on high technology in this mechanistic paradigm. Health expenditures rose from 13.8% to 17.6% of the gross domestic product (GDP) between 2000-2009, that is from \$1,380,000,000,000 (1.38 trillion) to \$2.45 trillion (Health & Human Services, 2009, historical Table 1). Medicare expenditures were about \$500,000,000,000 (500 billion or ½ trillion) in 2009 and about 30% is spent in the last year of life. About \$50 billion is spent in the last month of life, most on life sustaining treatments like ventilators and resuscitation (Zhang et al., 2009).

Healthcare has become one of the most profitable businesses in the country and to maintain this profitability, the mechanistic paradigm must be maintained. To address issues related to chronic illness and inevitable death, a more probabilistic approach to healthcare must be taken. More research is needed to uncover what people need to know to address the inevitability of death and their knowledge, attitudes, and perspectives about

advance care planning. This is an issue for all Americans but is especially concerning in minority populations in general and for African-Americans in particular.

Research paradigms. Once the philosophical grounding was established, the researcher identified the paradigm that would guide this research. Wilson (2008, pp. 33-34) defines a research paradigm as a set of beliefs or assumptions that underlie or guide the researcher's actions. These assumptions are based on theory and are value laden. Wilson (2008, p. 35-37) discusses Guba and Lincoln's four major research paradigms: positivism, post-positivism, critical theory and constructivism. These theories have overlap but can roughly be viewed on a continuum.

In positivism there is one reality and it can be broken down through objective thought. Scientific research that manipulates the smallest components of nature to find *cause and effect* relationships uses this paradigm. Positivism does not lend itself to humans as there is rarely a *single* cause that affects the human experience. Post-positivism is slightly different in that there is one reality but this paradigm acknowledges that objective thought is not possible and *reality* can never be obtained. The scientific rigors of validity and reliability are the goals of qualitative researchers in the post-positivist paradigm. In both of these paradigms, the pursuit of knowledge is the goal and the ends justify the means therefore the ethical treatment of subjects was not a priority until recently (Wilson, 2008, pp. 35-36). African-Americans have suffered unthinkable atrocities in these paradigms; many are outlined by Harriet Washington (2006) in her book, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*. The Tuskegee Syphilis Study was

conducted in the positivist paradigm and remains the longest unethical experimentation conducted on humans in the world.

Critical theory has a more fluid truth. This paradigm acknowledges that research is affected by the investigator's gender, social, and cultural values. This paradigm uses transactions between researcher and subject to inform consciousness and to change and improve reality. Methodology utilizing critical theory is aimed at promoting change to improve society (Wilson, 2008). The researcher should acknowledge what he or she is bringing to the table in terms of personal values and world view. The researcher should also partner with community participants on a level playing field to get honest input and feedback.

In constructivism, reality is as varied as people and their beliefs. This paradigm stresses interaction and dialog between researcher and subjects to come to a consensus about reality. The goal is to find common meaning and mutual reality between researcher and subjects but it begins with the subject's reality (Wilson, 2008). A consensus about reality should lead to a mutual understanding and valuing of the investigation and outcomes. This understanding and valuing should lead to a greater commitment of all participants to make changes recommended by outcomes.

Paradigms Selected for this Research

This research is conducted in the critical theory - constructivism paradigm. As stated earlier, there is some overlap of these paradigms and this research pulls from both. The present researcher is an African-American nurse who has worked in critical care most of her 35-year career, but in other areas as well. The present researcher has

experienced many situations where families and providers (nurses, doctors, social workers, etc.) were in distress over matters requiring critical health care decision making. It is difficult to provide quality end-of-life care to patients and families when there has not been prior discussion and planning about what the patient might want. The present researcher conducted an investigation with critical care nurses regarding their perceived obstacles and supports to providing quality end-of-life care; she found that seven of the top ten obstacles were things that could be changed or improved if patients had written advance directives (Crump et al., 2010). While the researcher identified the research question from the perspective of her practice, it is important that the perspective of the African-American senior community be equally represented in this research. This research paradigm was chosen to address the issue of advance care planning with African-American seniors because it provides the best opportunity to fully engage, on an equal playing field, with the participants.

The approaches utilized to conduct this research in the critical theory–constructivism paradigms are community-based participatory research with focus group interviewing. These approaches were guided by a community advisory board. Finally, a virtue ethics framework was utilized to insure certain ethical considerations. These elements in the approach are further described here.

Community-based participatory research (CBPR). CBPR is not a methodology but an orientation to how research is conducted. It is an equitable collaboration between the researcher and the community, and recognizes unique strengths of each. CBPR begins with a topic that is believed to be important to the community but

various aspects and approaches to the issue should be sorted out by the researcher and community members. The knowledge and experience of community participants is as important as knowledge and experience of the researcher. In this orientation to research, as in any other, specific attention should be paid to: power gradients, gender, race, social class, and culture. Other considerations are trust and racism. Again we are reminded of the Tuskegee Syphilis Study and the legacy of distrust it left in communities of color (Minkler & Wallerstein, 2003). The aim of this type of research is to improve the health of the community and eliminate health disparities by combining the action and knowledge of the researcher and the community. This orientation to conducting research is consistent with the critical theory–constructivism paradigms.

Community advisory board. A community advisory board is commonly sought in the conduct of CBPR to create an equitable collaboration between the researcher and the community. Community-based participatory research and the critical theory–constructivism paradigms require this equality. A community advisory board serves to mutually guide, lead, and contribute to the project with the professional researcher in order to optimally blend the interests of the investigator with the interests of the community in the context of the research. Wilson (2008) states there should be a level playing field with the opportunity to exchange honest input and feedback. A board was created for the conduct of the present research and is further elaborated in the methodology chapter. The community advisory board ensured the integrity of the researcher and research process from the community perspective of African-American seniors.

Focus groups. According to Krueger and Casey (2009), the purpose of a focus group is to listen and gather information to find out how people feel or think about an issue. Focus groups are small groups of five to ten similar types of participants. In focus groups, a skilled interviewer uses non-directive interviewing and open-ended questions to encourage participants to share their perspectives about an issue. Participants are not pressured to vote or reach a consensus. Focus group analysis is aimed at identifying trends and patterns in perceptions of the participants. Focus groups promote self-disclosure and work well when participants feel comfortable, respected and are in a trusting and non-judgmental environment.

The present research utilized focus groups as the qualitative approach to knowledge production regarding perspectives on advance care planning within one African-American community in the Twin Cities. This approach was selected because of its orientation that aligns with critical theory–constructivism paradigms. Focus group research in communities for the purpose of knowledge production constitutes community-based participatory research. All of the focus groups held as part of the present research were conducted by the present researcher/principal investigator.

Virtue ethics framework. A researcher should exhibit certain virtues to enter into trusting relationships with any individual and these virtues are particularly important when entering into a relationship with people from culturally diverse communities. According to Shaffer “virtues are strengths of character and contribute to habits of behavior” and virtue ethics are strengths of character defined by communities with a central notion of caring for one’s community (Schaffer & Norlander, 2009, p. 84). “A

Virtue Ethics Guide to Best Practices for Community-Based Participatory Research” by Marjorie Schaffer (Schaffer, 2009) has been selected as the framework for this research, and the framework is elaborated below.

Considering the good for the community may conflict with individualism or autonomy and vice versa. The researcher should be careful in determining what is important, and to whom, as well as the potential harmful consequences to the individual and the community. Often harmful consequences are not known or difficult to anticipate. The researcher must, in good faith, try to uncover all potential consequences of the research and be as transparent as possible in recruiting for, conducting, interpreting and disseminating research. The six virtues that Schaffer (2009) has identified as foundational to establishing ethical relationships when conducting community-based participatory research are *compassion, courage, honesty, humility, justice and practical reasoning* (Schaffer, 2009) p. 83. These principles constitute the framework used in conducting the present research, and are elaborated below. Following each short definition is a brief example of how the researcher has exhibited these virtues.

Compassion. ...compassion has three elements: the empathetic understanding of conditions that contribute to suffering and health problems, a corresponding affective response (feeling), and a desire or action to comfort and relieve suffering. Compassion results in making a connection with others based on a sense of commonality of human experience (Schaffer, 2009) p 86

The present researcher was born in the southern United States before the civil rights movement and shares the “Negro” experience of seniors in the United States. The

researcher has been involved with African-American senior activities in this community for the past four years and has been accepted as a member of the community. In various nursing roles, the researcher has had many years of experience with patients who are experiencing decision making dilemmas in end-stage-disease and end-of-life situations, and has noted many dilemmas with African-American patients in particular. The researcher hopes to make a compassionate connection with participants to find a mutually acceptable solution to this issue.

Courage. “Taking on the virtue of courage in CBPR requires researchers to examine their own intent and goals in the research process and recognize and acknowledge their own important values as well as those of the community” (Schaffer, 2009, p. 86).

For many years the researcher has believed that advance directives were essential to the care of patients with end-stage-disease and/or end-of-life situations. The original approach of this research was to present the participants with information about the value of advance directives and follow-up to see if they wrote an advance directive after receiving this information. After further review of the literature and consulting with the *community advisory board* of seniors from this community, the researcher recognized that the community dwelling seniors’ perspectives about advance care planning was really most important.

Honesty. According to Schaffer (2009), “Honesty means upholding the truth, avoiding deceit, and being sincere with others” (p. 86). Schaffer further states that honest

dialogue is more likely to succeed if the researcher builds trusting relationships and is willing to accept honest feedback about their performance and interactions (p. 86).

Health professionals use the terminology “end-of-life decision-making” to address issues of advance care planning. Many, if not most, seniors think of after death issues such as estate wills, burials, funerals and other after death issues when the term end-of-life is used (Schaffer & Norlander, 2009). The researcher has closely examined the intent of this research and is comfortable that asking “who would speak for you if you were very sick and unable to speak for yourself” does not constitute dishonesty. The researcher was able to conclude this after discussions with community seniors. This led to the formation of a community advisory board to ensure honest exchange throughout the research process.

In further examining the virtue of honesty, the present researcher also took another look at the origins of advance directives and their value from the perspective of the individual, the African-American community, the health care system, and professional caregivers. In doing so, several issues regarding advance directives as a fiscal conservancy and empowerment of personal decision-making were discovered. The Patient Self Determination Act is a subpart of the Omnibus Budget Reconciliation Act, which was a process to reduce the federal budget deficit (Library of Congress THOMAS, 1990). The connection of advance directives to a budget reduction process has tainted its value as “simply” a self-empowering decision making tool (Baker, 2002) and the researcher disclosed this fact as part of the informed consent process.

Humility and justice. Underscoring the importance of CBPR is the fact that “for CBPR, the virtue of humility can guide the researcher to examine the inadequacies in their own understanding of community experiences and viewpoints as well as examine both knowledge and lack of knowledge in implementing the research process” (Schaffer, 2009, p. 87). An assessment of justice must focus on fairness and the common good for the community. Community consent would likely precede individual consent and there would be equitable involvement of the community. Potential consequences of the research would be assessed for the community as well as the individual and findings should contribute to improved social conditions. Community members should be co-researchers and all transactions and interactions should be transparent (Schaffer, 2009).

From the perspective of the African-American community, the literature thus far indicates that African-Americans tend to prefer more high tech care at the end of life than white Americans (McKinley, Garrett, Evans, & Danis, 1996; Phipps et al., 2003; Waters, 2001; Waters, 2001). Does this mean that research which might confirm this as fact could lead to African-Americans having increased health care insurance premiums or being refused life-saving care, a concern of participants in the Water’s study (Waters, 2001)? Potential outcomes such as these are not known but were explored with participants as theories to consider as part of the informed consent and focus group process. As detailed fully in the methodology, the present researcher assembled a team of community seniors, seniors with whom mutual respect exists and honest feedback can be shared, as a community advisory board to provide guidance and feedback with the entire research

process including recruiting, focus groups, data analysis and reporting of findings; the process of their engagement in the research was documented in detailed notes.

Practical reasoning. Schaffer defines practical reasoning as “the capacity or ability to have moral insight about a situation... a systematic process that involves recognizing relevant factors, identifying a goal related to the specific situation, and setting priorities to achieve the goal” (Schaffer, 2009, p. 88). The researcher should be prudent, have reasonable expectations and learn from the collaborative relationship. The researcher identified trusted leaders in the community to give direction and honest feedback in every step of the process.

Summary of virtue ethics framework. The Virtue Ethics framework was selected because it fits with the present researcher’s philosophical grounding and paradigmatic perspective. This framework enabled the researcher to meet the goal of ethically exploring African-American seniors’ perspectives on advance care planning and writing advance directives. The virtue ethics approach identifies methods to help nurses and other healthcare practitioners understand ethical and cultural considerations when attempting to assist African-Americans with advance care planning. The researcher’s goal of improving the experience of patients and health professionals who find themselves involved in end-of-life situations has helped to identify the current research question and approach to this research.

The evolution of advance care planning and significant cases that have influenced this evolution are discussed in the following section.

Advance Care Planning vs. End-of-Life Decision Making

The end-of-life is death... or is it? Most people are not able to envision the dying process and even if they have experienced it with a friend or relative, they tend to deny it for themselves. That is, even when patients have had experience with a dying person and confusion around the decision making, they seem no more likely to have named someone to speak for them in anticipation of a time that they may be unable to speak for themselves (Caralis et al., 1993). Americans, in general, tend to be reluctant to talk about death and dying and to treat death with a war metaphor, to be fought with every possible resource. For many African Americans, death is seen as a just another health and social disparity and therefore just another struggle to overcome, a bridge to cross when you get to it. As such, denying the dying process can be a way of not acknowledging that they do not believe that they will get the same quality of care as white Americans if they are dying. Denial can be a healthy response to situations that you have no control over (Collins et al., 1995), but there are many decisions that must be made in critical healthcare situations when an individual is not able to speak for him or herself.

Health professionals use the terminology “end-of-life decision-making” to address issues of advance care planning. Many, if not most, seniors think of after-death issues such as estate wills, burials, funerals and other after death issues when the term end-of-life is used (Schaffer & Norlander, 2009). For some cultures, talking about end-of-life situations or death and dying are taboo (Johnstone & Kanitsaki, 2009), and this is often the case in African-American senior communities. Using the professional language of *end-of-life decision-making* has been found to be obstructive and not conducive to

engaging African-American seniors in an advance care planning conversation in a way that allows them to freely express their thoughts and feelings about the matter (Waters, 2001). The present researcher has closely examined the intent of this research, and this led to using the term *advance care planning* when working with this population. The use of the term “advance care planning” rather than “end-of-life decision-making” is in no way intended to be deceptive and was routinely disclosed to the participants. The literature uses these terms interchangeably and these terms are used interchangeably throughout this paper.

Advance directives—an overview. Informed consent and advance care planning are the result of numerous events in history. The 1970s consumer rights movement was aimed at shifting some of the decision making for healthcare from the physician to the patient. That led to the 1972 American Hospital Association’s Patient’s Bill of Rights (American Hospital Association, 1992). A few years later in 1976, Karen Ann Quinlan’s case started the public discussion about advance directives (Armstrong, 1976). The Nancy Cruzan case led to case law and the Patient Self Determination Act (PSDA) in the 1990s (Library of Congress THOMAS, 1990). The Terri Schiavo case has brought this discussion into the 21st Century (Quill, 2005; Schiavo & Hirsh, 2006). A brief overview of these events follows.

Karen Ann Quinlan. This case provides the basis for the establishment of hospital Ethics Committees and furthered the discussion of surrogate decision making in end-of-life. On April 15, 1975, 21 year old Karen Quinlan ceased to breathe for unknown reasons [she is alleged to have taken drugs and alcohol]. Resuscitation efforts of friends

and emergency services were ineffective. Within three days she was decorticate (a condition of derangement of the cortex of the brain) and ventilator dependent, but her condition did not meet the then (1975) criteria for brain death. Soon, she was diagnosed as being in a chronic persistent vegetative state, and there was agreement that no medical treatments or procedures offered any hope of recovery. Karen's father, Joseph Quinlan, consulted with Catholic Church leaders and requested to act on his daughter's constitutional right to withdraw treatment since she was incompetent to do so. He wanted to remove the extraordinary means being used to maintain his daughter's bodily functions citing the First Amendment (freedom of religion) and Eighth Amendment (right to avoid cruel and unusual punishment) of the Constitution (Armstrong, 1976). The New Jersey Supreme Court recommended that Ethics Committees be established to provide guidance to providers, patients, and their families in such situations. They appointed Joseph Quinlan as Karen's guardian and decision maker, along with the guidance of an Ethics Committee in March, 1976. The ventilator was removed in 1976 but Karen did not die until 1985.

Nancy Cruzan. The first "right to die" case was heard by the United States Supreme Court regarding Nancy Beth Cruzan in 1990. There had been other cases about rights to refuse treatments for various reasons but this was the first case about the need for "clear and convincing evidence" before a surrogate could remove nutrition and hydration from a patient (who was not brain dead) which would lead to their death (Cruzan, 1990).

Nancy Cruzan became incompetent in 1983, at the age of 25, after injuries sustained in an automobile accident, in the state of Missouri. She was estimated to have been deprived of oxygen for 12-14 minutes, was in a coma for several weeks, and quickly progressed to a persistent vegetative state. Nancy was known to have expressed to a friend “in somewhat serious conversation” that she would not want to live in such a state. The Missouri courts found that a person in her condition had the right to make decisions to refuse or direct the withdrawal of procedures that would do no more than prolong death. After about five years in this comatose incompetent state, her parents, Lester and Joyce Cruzan (co-guardians), requested to discontinue artificial hydration and nutrition. Nancy was not receiving artificial respiratory ventilation. The Missouri Supreme Court held that her parents did not have the authority to discontinue these life sustaining treatments because they did not have *clear and convincing evidence* (consistent with the state’s living will statutes) that this was Nancy’s desire.

The United States Supreme Court upheld the Missouri Supreme Court decision June 25, 1990 (Cruzan, 1990). However, three more of Nancy’s friends stated that Nancy had told them that she would not want to live in such a condition and on December 14, 1990 a Missouri circuit court ruled that this new information constituted *clear and convincing evidence* and the feeding tube was removed. Nancy Cruzan died on December 26, 1990. This decision firmly established the challenge of a legal next of kin’s right to decide a person’s preferences if the person was in an end-of-life situation and their wishes were not written.

Terri Schiavo. The debate involving the case of Terri Schiavo was high profile and prolonged over about the last eight years of her 14 year disability. The debate was primarily about the right of the legal next of kin to decide and act in the best interest of the person. This case involved the Florida courts, the Governor of Florida, the United States Congress, and the President of the United States (Eisenberg, 2005). Considerable detail is outlined about this case because of its high profile nature and the fact that most of the discussion has occurred with the most recent laws in effect.

Terri Schiavo suffered a cardiac arrest, presumably from a potassium imbalance caused by an eating disorder, on February 25, 1990. Her husband of five years, Michael Schiavo, was her legal decision maker in accordance with Florida law. By April Terri was declared to be in a persistent vegetative state and in June, 1990 Michael Schiavo became her legal guardian. Terri's insurance company did not want to pay for rehabilitation because she was not believed to have any rehabilitative potential but Michael insisted and she was moved to a nursing home with the ability to provide rehabilitative care. By the fall of 1990 Terri was not making any progress and in November she was taken to the University of California at San Francisco hospital for some experimental treatments. After no improvements were realized there, she returned to Florida and was admitted to a rehabilitation facility in January, 1991. Terri made no progress at the rehabilitation facility and was sent to a nursing home in July, 1991. Michael filed a lawsuit against her doctors and won \$2.2 million, and after expenses he received \$300,000 for loss of consortium and \$750,000 for Terri's care. After the

settlement, his relationship with Terri's parents began to break down (Quill, 2005; Schiavo & Hirsh, 2006).

In July, 1993 Bob Schindler, Terri's father, filed suit to take over her guardianship. In 1994, Michael did not want Terri to have treatment for an infection and this began a vicious fight between the Schindlers and Michael Schiavo. In 2001, Michael wanted to remove Terri's feeding tube which would lead to her death. A guardian is expected to act in the *best interest of the person* but there is no agreement about whether a feeding tube is in the best interest of a person in a persistent vegetative state. Florida law also requires *clear and convincing evidence* that a person's known wishes are being followed. However, unlike the Cruzan case, Terri's parents disagreed with Michael about whether Terri would want the feeding tube removed. Terri's feeding tube was removed three times between 2001 and 2005 with numerous lawsuits filed by her parents to have it reinserted. Terri's parents lost all of the lawsuits but the feeding tube was reinserted twice pending outcome of litigation and appeals. When the feeding tube was finally removed on March 18, 2005 the case was appealed to the U. S. Supreme court. A *compromise bill* (S. 686) was passed in Congress over the weekend and signed by President George Bush on Monday, March 21, 2005 (PL 109-3) to allow the Shindlers to have the tube reinserted (109th Congress, 2005). This bill was overturned as were all other legal efforts to reinsert the tube and Terri Schiavo died on March 31, 2005 (Quill, 2005; Schiavo & Hirsh, 2006; Whittemore, 2005).

Impact of Quinlan, Cruzan and Schiavo. Quinlan, Cruzan and Schiavo were all under the age of twenty-five when they entered end-of-life (EOL) situations. When we

talk about EOL decision making and healthcare policy, we are most often talking about the personal right to make decisions about what cares one would want if he or she were in an end-of-life type of situation and unable to speak for him or herself. If there is nothing in writing, a dilemma often ensues. As a result of the Cruzan case the courts decided that there must be clear and convincing evidence of what a person's wishes were if they did not have them in writing. If this evidence is not available, the decision goes to the legal next of kin and it is recommended that an ethics committee assist with any dilemmas that might arise. The Patient Self Determination Act provided for a number of methods to operationalize the concept of self-determination; among these are living wills, durable power of attorney, and health care proxy. The role, differences, effectiveness and manner of use are described below.

Living Wills, Durable Power of Attorney for Healthcare, Healthcare Proxy

In December of 1991, Congress enacted The Patient Self Determination Act (PSDA). The PSDA requires that patients be presented with information and the "opportunity" to write an advance directive upon admission to a healthcare facility. This provision is contained in the Omnibus Budget Reconciliation Act of 1990 (Library of Congress THOMAS, 1990). The goal of the PSDA is to protect patient's right to self-determination even if they are unable to speak for themselves (Blackhall et al., 1999; Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998; Giger, Davidhizar, & Fordham, 2006).

Living wills (LW) are used to advise what a patient's wishes are if he or she is unable to speak in a critical healthcare situation. They are usually written instructions

about particular treatments such as cardiopulmonary resuscitation (CPR), mechanical ventilation, feeding tubes, and hemodialysis that a person would want in a particular kind of circumstance. In some cases and some states, advance directives or living wills do not go into effect until, and unless, the person is believed to be dying. It varies from state to state and throughout the literature, however, the term *advance directive* is often used interchangeably with *living will*.

A durable power of attorney for health care (DPA-HC or DPOA-HC) or healthcare proxy authorizes a person to speak for someone who is unable to speak for her or himself in critical healthcare situations. Absent a LW and/or DPOA-HC, the family, in order of legal next of kin, becomes the decision maker. The family is expected to act in accordance with the patient's wishes and/or in the best interest of the patient.

The two documents (LW and DPOA-HC) taken together are called an advance directive or an advance care plan in some literature; in other literature they are considered separately. An advance care plan can include a third thing, a values assessment or goals for outcomes of care that inform the treatment choices or decisions. Although the forms and formats may be different, the underlying principle is patient autonomy, the right to decide what should be done to one's person (Fagerlin et al., 2002).

There are other aspects of advance care planning that are very important. These include discussion with family and healthcare providers and documentation in the healthcare records. The discussion with the healthcare provider can be documented without a formal advance directive but would likely be more difficult to transfer and locate in the patient's medical records. The discussion of values, goals and preferences or

wishes should be done with family and should include the decision maker and other next of kin. Privacy laws, such as the Health Information Portability and Accountability Act (HIPAA) (Health and Human Services, Office of Civil Rights, 2003), dictate that identifiable information about a person may not be released to an unauthorized person and enforcement of this rule has taken a zero tolerance stance recently (McClendon, 2010). Therefore, if a person wants the decision maker to be someone other than the legal next of kin, they *must* have a durable power of attorney for health care.

According to a Pew Research study of 1500 adults that was conducted in November, 2005, approximately 29% of participants claim to have a living will which is up from 12% in 1990. Fifty-four percent of seniors claimed to have a living will. If a person had been involved in decision making for a terminally ill friend or relative, 85% were more likely to have talked with their spouse about treatment, about 64% had given a lot of thought to the matter but only 45% had completed a living will. If they had not had an experience with a terminally ill friend or family, the results were only 65% (talked), 28% (thought about) and 28% (wrote) a living will. Only 19% said they had not discussed their end-of-life wishes with anyone and another 10% said they had not given the matter any thought. Eighteen percent of white respondents chose to “always do everything possible to save a patient’s life” while 51% of blacks wanted to do everything (Pew, 2006).

Living will as preventive health behavior. To understand why there are such low levels of completion of living wills, Fagerlin et al. suggest considering a living will as a preventive health behavior. They used Rosenstock’s 1974 Health Belief Model

(HBM) to explain the lack of proactive behavior toward advance directives. The four basic principles of the HBM, which explain proactive behavior, are peoples' perception of "susceptibility to the condition, severity of the condition, benefits from engaging in the behavior, and barriers to engaging in the behavior" (Fagerlin et al., 2002, p. 271). The authors suggest that people do not perceive the threat of lingering death as applying to them and thus do not see the benefits of having a living will, and/or they simply procrastinate about completing them. They suggested that "comprehensive strategies of advance care planning that incorporate discussions with physicians and family members in a way that most effectively communicates patient wishes to those who will implement them" are needed (Fagerlin et al., 2002, p. 277). They stated that no research to assess the psychological effects of advance directives and the relationship to patient's self-determination or autonomy was done before advance care plans were instituted by the Patient Self Determination Act of 1990 (Fagerlin et al., 2002).

It appears that people are most interested in delegating decision making to a family member they can trust with the process. Fangerlin et al. (2002) suggest that naming a durable power of attorney for health care is a good time to initiate meaningful discussion regarding the patient's end-of-life treatment wishes and values. They recommended that future research be conducted to gain a deeper understanding of the psychology of end-of-life decision-making, and thereafter to establish policies that are effective in improving the dying process for patients and families. There is considerable information in the literature that suggests that the low levels of completion of advance directives may have more to do with other factors that have not yet been studied (Bullock

et al., 2005; Caralis et al., 1993; Dupree, 2000; Eleazer et al., 1996; Gerst & Burr, 2008; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998; Murphy et al., 1996).

Clearly more research needs to be done in this area. A review of literature was conducted to examine what is known about the attitudes and perspectives that African-Americans hold about advance care planning, and to determine what questions and challenges remain.

Review of Literature

This literature review was conducted to undergird the study and to identify and analyze literature related to attitudes and perspectives of African-Americans about advance care planning. A preliminary search was also conducted to provide perspectives on the topic and the range of evidence available. This search was followed by a more focused search; the method for the focused search is described below along with the search strategy, inclusion and exclusion criteria.

The preliminary search of the literature was conducted to understand the content and organization of the field. In this preliminary examination of the literature, it was found that most of the literature about advance care planning focused on decision-making in situations where death appeared imminent. End-of-life care planning requires thinking about exactly what care and treatment one would want if one were dying. However, who would speak for a person who is unable to speak in a critical healthcare situation is a slightly different issue than *end-of-life* care planning. Therefore, the subsequent literature review was focused on the *perspectives* of African-American seniors making decisions

about who would speak for them if they are not able to speak for themselves in critical healthcare situations.

Many decisions need to be made in critical healthcare situations, and often the patient is not able to speak for some period of time. Many times this *could be* an end-of-life situation, but that is not necessarily the case. Most people who have surgery or are in an intensive care unit (ICU) are unable to speak for some period of time and most of them recover and leave the hospital. However, during that time, it is important to insure that a patient's wishes are known and they have identified the person they want to communicate those wishes. Therefore, in the subsequent literature review underlying the present research, the search was focused on advance directives; that is work done to consider and write an advance directive before a serious illness occurs.

Finally, through the preliminary review, it was found that there have been several studies examining attitudes and perspectives of completing advance directives, but few have examined attitudes and perspectives of minorities toward advance directives and advance care planning. Some studies reviewed compared several minority groups while others compared one minority group to the white majority. The present review was focused on studies investigating older participants who were African-American. This includes studies comparing African-Americans to whites, or studies comparing several groups, including African-Americans and whites where data for African-Americans are reported separately. This review also focused on the choice to execute a living will and/or durable power of attorney for health care, either verbally or in writing. Preferences for particular treatments were often reported as findings of choosing to, or not to, execute an

advance directive. While those preferences are often important to the decision to execute an advance directive, the preferences themselves are not the focus of this research.

Inclusion and exclusion criteria. Inclusion criteria for the focused search included studies published in English which identified key findings on African-American decision-making regarding advance directives, advance care planning and end-of-life decision making. Articles that included decision-making around specific diagnoses and treatments, or other end-of-life issues were included if they had data regarding advance directives; even if they did not specify that they were related to advance care planning or writing advance directives. Special attention was given to articles that included seniors/elders/older adults and race, ethnicity and/or culture. Articles that addressed recruiting for or conducting such research were also sought.

Articles that addressed racial or ethnic diversity of other races were included if they also included blacks but generally only the studies comparing African-Americans to white Americans were included. General information regarding the history of advance care planning and the ethics and history of research with African-Americans was also reviewed. Pediatric literature was excluded. Those studies that examined attitudes and perspectives in general and included African-Americans in the sample but did not report the findings for African-Americans separately were excluded. Studies that examined advance care planning with other minority groups but did not include African-American participants were also excluded.

Search strategy. The literature search was conducted in PubMed, OVID and CINAHL databases from the years 1990 to 2010. The year 1990 was chosen as a start

point because the Patient Self Determination Act was enacted that year and it constitutes 20 years of review. Key words used for the search included 'end-of-life,' 'terminal illness,' 'advance care planning,' 'advance directives,' 'minority,' 'African-American,' 'blacks,' and 'healthcare decision making' in the titles or abstracts. The bibliographies for acceptable studies were reviewed and relevant citations were cross-referenced.

Analysis and Interpretation of the Literature

There is a difference between advance care planning, end-of-life decision making and deciding about treatment options in critical healthcare situations. None of these things are necessarily the writing of a living will or a durable power of attorney, but they can be. There is considerable overlap in how research is done in this area. The researcher read the various articles in the search to get at anything that could give some insight into the very complex issues that affect African-Americans' views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives.

The following studies were selected because of their focus on the attitudes and perspectives of African-Americans towards advance care planning and the writing of advance directives. Some of the studies looked at treatment preferences but included information about the perspectives and attitudes of the patients and/or caregivers. Other studies are included in the summary for their agreement or disagreement with these studies. The relevant studies identified were organized into quantitative, qualitative and mixed methods studies; a description of these individual studies, by category, is followed by a synthesis of the literature.

Quantitative studies. Two large national retrospective studies were found that looked at end-of-life planning in institutionalized and community dwelling seniors. Both were sizable studies with a broad sampling of African-Americans' perspectives represented.

Gerst & Burr (2008) conducted a large study (n=1102) with data that was obtained from the Health and Retirement Study of 2005. They compared differences in end-of-life healthcare planning of black (n=191) and white (n=921) community-dwelling and institutionalized patients who had died between 1998 and 2000. This study differs from most in that it examined advance directives in three ways; verbal discussions of wishes as well as written directives (living wills) and durable power of attorney for health care (DPA-HC). Overall 38% of participants completed written documentation (living wills) with whites (42.9%) completing them at more than three times the rate of blacks (13.3%). While the overall completion rate for a DPA-HC was 44.4%, whites (48.3%) were twice as likely as blacks (24.3%) to complete one. Age ranged from 48 to 105 years with an average of about 79 years. Age was comparable for both groups. There were many other variables in the equations (such as gender, marital status, history of recent hospitalization, religion and net worth) but when they were controlled, there were still strongly significant black-white differences (Gerst & Burr, 2008).

Investigators concluded that “some sociocultural groups, such as Blacks, hold different belief sets influencing whether a person feels comfortable discussing or planning for end-of-life care” (Gerst & Burr, 2008, p. 444). They recommended that more qualitative research be done to explore attitudes.

Eleazer et al. (1996) conducted a retrospective chart review of 1193 participants in the Program for All Inclusive Care Of the Elderly (PACE). The study included 12 national sites which did not have even racial distribution (some sites were mostly all Hispanic, black or Asian). There were 385 whites, 364 blacks, and 444 Asians and Hispanics included. Whites were an average three years older than blacks, 80 to 76.4 years respectively, and had about one and one-half more years of education, 10.0 to 8.4. More whites were married (20.8%) compared to blacks (18.4%) and blacks were significantly more likely to have living children (68%) than whites (61%).

There was little difference in the recording of healthcare wishes of blacks (80%) and whites (76.4%) in the records. Completion rates for blacks and whites were low for the durable power of attorney (28% white; 5% black), the HC proxy (20.5% white; 7% black), and extremely low for the living will (2.3% white; 0.3% black). The researchers thought that blacks might not sign advance directives because they were reluctant to “sign anything” due to their history of negligent treatment and their poor education. Since this study is only about what was documented in the record, they do not know if records were documented differently based on ethnicity of patient and/or provider or other reasons. However, these findings indicate that there needs to be cultural sensitivity when presenting minorities with options for advance care planning (Eleazer et al., 1996). They further recommend that qualitative research be done to explore why blacks are reluctant to sign advance care planning documents.

Qualitative studies. Many things can influence attitudes and perspectives about writing advance directives. Qualitative studies, by their nature, can get at things that are

not just important to be counted but to more deeply understand the why or the how. Thus, these are important considerations for the present research. The majority of studies after 1993 that are related to African-Americans' attitudes and perspectives about advance care planning or treatment options cite Caralis et al. (1993). Perkins et al. (2002) sought to generate hypotheses about perspectives and gain more insight into cross cultural similarities and differences in knowledge and attitudes of African-Americans, European-Americans and Hispanics. They used a rigorous coding system and despite the small size of the study they are frequently cited. Waters (2001) conducted a community based study similar to what this research proposes and is outlined in detail.

Caralis et al. (1993) investigated the influence of race and ethnicity on the knowledge and attitudes of African-Americans (n=51), Hispanics (n=39) and non-Hispanic whites (n=49) toward discussing advance directives and life prolonging therapies with their families and physicians. They utilized a standardized survey to ask these participants about specific preferences for treatments that would allow them to die in response to six specific circumstances. Since total numbers include Hispanics, all groups are reported in part here.

About half of each group was of a low socioeconomic status and each group had about an equal number of chronic illnesses. They compared the three groups' responses and found that, overall, 56% claimed they knew what an advance directive was, although only 45% were able to properly define the term. Fifty-one percent of African-Americans were knowledgeable about the documents compared to 77% of non-Hispanic whites. Nineteen percent of the total population said that they learned about living wills from the

media, with only 10% saying that they learned about them from their physician. Eighty-three percent agreed with the purpose of a living will. Forty-two percent of the total patients had already executed an advance directive, which was fairly evenly distributed across all groups (Caralis et al., 1993).

African-Americans were more likely to feel that they would get less care if dying and were more likely to distrust the healthcare system. Most of the patients felt that doctors should not make decisions unilaterally; they preferred families' wishes be honored when there was conflict. While most patients declined life-prolonging treatment when they were in a persistent vegetative state, African-Americans were most likely to desire treatment in all disease states. The Caralis et al. study suggested that socioeconomic factors influenced patient's knowledge and understanding of advance directives but did not influence their attitudes and treatment preferences. They suggest that "attitudes and choices are influenced by deeply ingrained social and cultural values" (Caralis et al., 1993, p. 165).

Perkins et al. (2002) surveyed 26 Mexican-Americans, 18 Euro-Americans and 14 African-Americans between the ages of 50 and 79. One hour long interviews were administered to the participants by culturally sensitive bilingual interviewers to generate a hypothesis that characterized the participant's attitudes about advance care planning. The interviews elicited the participants' knowledge of advance directives and durable power of attorney, how they felt about them and whether they would sign one. Four coders read and re-read the transcripts and determined there were 82 themes related to advance directives. The themes had to be agreed upon by at least two coders as

significant to at least 50% (arbitrarily defined) of the ethnic group. Of the 82 themes, 26 were determined to be significant. Group similarities were age, gender and employment status; groups differed in religious affiliation, marital status, education, occupational group, and economic status. Mexican-American and African-Americans scored 21 on the Duncan Socioeconomic Index while European-Americans scored 29 on the index.

Despite documentation that about 80% of each group had received information about advance directives upon admission, only 69% of European-Americans and 29% of African-Americans claimed that they had heard of advance directives. Further, only 31% of European-Americans and 21% of African-Americans recalled such discussions. The themes were classified under four major topics; “treatment wishes, expression of treatment wishes, advance directives, and decision making about terminal care” (Perkins et al., 2002, p. 50). Several themes were shared among and between groups but some were unique to a particular group. European-Americans and African-Americans shared two themes, “expression of treatment wishes to family and the belief that the existence of ADs just means the patient is imminently dying.” African-Americans were the only group who “believed they should wait until very sick to express their treatment wishes” (Perkins et al., 2002, p. 52).

The limitations of this study are its small, purposive sampling and potential confounding with other variables such as education, religion, etc. Strengths are the open ended interviews which allowed subjects to say what they felt in their own words. Also, interviewing older people in a rather ill state made death for them more real. Considerable rigor of the coders minimized bias in analysis. The similarities of the

groups probably reflect American culture in general with the differences representing ethnic differences in culture.

The findings specific for African-Americans are that they may readily share their wishes with their family but reluctantly with their physician. In this research, African-Americans believed the healthcare system controls treatment and few trusted the system to serve them well. They also felt they should not disclose their wishes to physicians until they were very sick. The researchers found that physicians should initiate conversations, listen to patients and help them define and express their treatment wishes. Providers should also try to remove obstacles to the process and include family members to the extent that the patient wishes. The researchers stated future research should continue to explore ethnic and culture based attitudes about dying (Perkins et al., 2002).

Shrank et al. (2005) explored communication around end-of-life issues, including preferences for what should be included and how information should be delivered. They used focus groups and a hypothetical scenario of a dying relative along with a structured interview to explore these preferences. African-American (n=34) and non-Hispanic white (n=36) patients were interviewed in six groups, separately, with a moderator of concordant ethnicity. The researchers stated that "...prior research has not been able to provide adequate guidance to healthcare workers who participate in end-of-life discussions, especially in cross-cultural communication contexts" (Shrank et al., 2005, p. 703). Their aim was to identify hypotheses that could guide providers in communicating about end-of-life care more sensitively. Advance directives were peripherally mentioned with African-Americans preferring a *family meeting* to complete the directives while

whites preferred the physician to initiate discussions about directives. The most consistent theme for the African-American groups was their faith in the healing power of God. This contrasted with the non-Hispanic white groups who tended to have faith in their physician and medicine to heal them. They state that the study confirms differences in preferences and values found elsewhere in the literature but they were unable to isolate the effects of ethnicity or other characteristics (Shrank et al., 2005).

Waters (2001) conducted a community-based, focus group study with 27 African-Americans (aged 27-69 yrs.) to explore their perspectives on end-of-life decision making and planning. The participants had a spirituality score of 3.73 on a tool (not named) with a range of 1-5 with 5 being highest level of spirituality. Except to say that participants “defined religiosity outside the context of organized religion and preferred the term spirituality” there was no explanation of how the score related to religious affiliation or their perspectives (Waters, 2001, p. 390). None of the participants had received life support but were “experienced” in that some (n=6, 22%) had made a decision to withdraw life support from a family member and 56% (n=15) knew someone who had received life support. Waters (2001) used a semi-structured interview guide with six broad questions:

(a) Have you heard of the term advance directives? (b) How do you feel about advance directives? (c) How would you feel about being asked to write a living will by a health care provider? (d) When, where, how, and who should begin discussions about living wills? (e) What type of end-of-life care planning and decisions have you made or would you

make? (f) Who should know? (g) Who should be involved in the decision-making process of planning care at the end of life? (Waters, 2001, p. 387).

Additional questions were asked to expand the discussion. The group facilitator was an African-American female nurse educator and the liaison was an African-American male psychology instructor at a local junior college who had been a research associate for several projects in the community (Waters, 2001). At the focus group meetings, a one-page sheet introduced the topic of advance care planning with questions and answers and a brief discussion. The groups were audio-taped, transcribed and analyzed with the NUD*IST qualitative research software program “in the context of understanding and supporting African Americans’ perspective of end-of-life care planning and decision making” (Waters, 2001, p.389). Waters’ analysis revealed six major themes:

(a) death is not an option, (b) religiosity and end-of-life planning is a paradox, (c) the health care system is a microcosm of societal and historical events, (d) a ‘trusted’ family member or friend is the contract for life-and-death options, (e) ethnically relevant initiatives are essential to increase advance directives participation, and (f) people are people (Waters, 2001, p. 389).

There were no discernable differences between the different groups, their age or gender. Waters contended that understanding these themes can help healthcare professionals to decrease the mistrust of African-Americans in all healthcare related interactions, including end-of-life.

The findings revealed that most participants felt that end-of-life planning was important but were not motivated to complete advance directives. The participants stated their families would carry out their wishes. However, according to Waters, healthcare professionals might find the need to communicate the same information to several family members frustrating. The participants in this study were reluctant to sign anything that would decrease their options because they believed they already receive less care and are offered fewer options than white Americans. Participants cited mistrust and negative experiences with the healthcare system for their preferences for aggressive end-of-life treatment and reluctance to sign an advance directive. They were also concerned that if it was known that African-Americans prefer to have more aggressive treatment it could alert insurance companies and affect their ability to obtain health insurance. Participants who had heard about advance directives did not hear of them from their healthcare providers but from friends or family members. This was also true for those who had executed an advance directive.

Based on the insights of this research, the investigator also stated that ethnically relevant, family centered, and community based educational programs should be developed (Waters, 2001). Because African-Americans are more likely to trust people who share their social fabric, it was suggested that African-Americans should be trained to be counselors who could reach out to community households, with general healthcare professionals providing information and consultation. There were also non-typical strategies identified such as educating juveniles about advance directives to help them recognize the impact of violence and homicide. Another strategy was to partner with

community centered organizations to conduct educational seminars about advance directives. Participants preferred advance directive discussions occur in the community rather than in an emergency situation. They also thought that these discussions “would flow easier from a spiritual perspective” (Waters, 2001, p.396). The focus group methodology was chosen because it allowed the participants to interact with each other. This was a convenience sample that was recruited through community liaisons and only one ethnic group was studied, so generalizability is limited. A clear finding of the study was that individuals need to “receive ethnically meaningful advance-directives education to reach ethnic minority populations” (Waters, 2001, p. 397).

Mixed method studies. The combination of qualitative and quantitative methods can support a more in-depth investigation of larger samples.

Phipps et al. (2003) used quantitative and qualitative methods to investigate attitudes, preferences and behaviors of 136 (68 pairs) of terminally ill (lung and colon cancer) patients. There were 38 African-American patients with 36 family caregivers and 30 white patients with 32 family caregivers. They gathered information from the health records and used concordant interviewers to interview participants (patients and caregivers) separately, using open-ended questions with probes. Their aim was to better understand the difference and agreement of the pairs associated with supporting patient autonomy, preferences for, and initiation of life-sustaining measures.

Most patients (98%) and caregivers (68%) said that the patient should be the primary decision maker but only 24% of patients had signed a living will (LW) and 19% had signed a durable power of attorney for health care (DPOA-HC). Whites (41% LW

and 34% DPOA-HC) were about four times more likely to have signed the documents than African-Americans (11% LW and 8% DPOA-HC). Sixty-nine percent of white patients and 54% of African-Americans said they had discussed their preferences with family but only one patient had discussed preferences with the doctor. The reasons given most for not having a LW, DPOA-HC or discussing preferences was that no one had brought up the subject to them; it wasn't necessary until they were closer to the end; they didn't want to distress the patient or family with the discussion; and assuming that the family would know their preferences without putting them in writing. Lack of knowledge was not cited as a reason for not completing the documents.

The overall agreement of patients and their caregivers was no more than chance on the patients' preferences for life sustaining treatments in the patients' current or near death situations, even when they had had discussions. However, African-Americans and their caregivers were far more likely to agree on the patient's desire for cardiopulmonary resuscitation (CPR) (patient 73%, caregiver 71%) in near-death conditions; and African-American patients were two to more than three times more likely to desire CPR (African-American 73%, white 31%), mechanical ventilation (African-American 58%, white 21%) or tube feeding (African-American 53%, white 17%).

Murphy et al. (1996) used a stratified sampling technique to study 800 individuals (200 African-American, 200 European-Americans and 400 Korean and Mexican-Americans) with equal numbers of males and females with similar age distribution (age 65+) in each group. They explored knowledge, attitude and completion rates of advance directives and the relationship to ethnicity. They used interviewers whose ethnicity

matched the four groups, conducted a one-on-one, hour-long interview, and administered the “Ethnicity and Attitudes Toward Advance Directives Questionnaire” which they developed. They used multiple statistical procedures to test for differences across factors such as education, age, ethnicity, religion and religiosity, income, functional status, experience with illness or end-of-life situations, and access to healthcare. European-Americans had significantly more knowledge (69%) than African-Americans (12%), were more likely to have a positive attitude (mean .31) than African-Americans (mean .19), and far more likely to possess an advance directive (28%) than African-Americans (2%). However, of those who had knowledge, 40% of European-Americans and 17% of African-Americans possessed an advance directive. African-Americans tended to have a positive attitude toward advance directives but this did not increase their possession. This study supports the premise that cultural groups have values and beliefs that affect their decision making regarding death and dying and may be differently motivated to seek out information (Murphy et al., 1996). Further qualitative research is needed to explore African-American seniors’ perspectives regarding this issue.

McKinley et al. (1996) conducted interviews with 92 black and 114 white ambulatory cancer patients. Their objective was to test the hypothesis that ethnic differences exist because black patients have less trust in the healthcare system, more fear of inadequate medical treatment, and feel less confident that living wills can give them more control over their terminal care. They found that black and white cancer patients make different choices even after controlling for variables such as age, gender, religion, income and stage of cancer. The participants in this research did not differ in their

perceptions of trust and equality of the healthcare system, nearly all (96%) of both groups expressed that they trusted that they would be treated well. However, blacks (18%) were twice as likely as whites (9%) to believe that living wills increase hopelessness; and three and one-half times more likely to believe that living wills decrease the quality of medical care (blacks 14%; whites 4%). Blacks (3%) had fewer living wills at the beginning of the research than whites (34%) and were less likely to complete an advance directive in the future. The researchers found no explanation for these differences. The researchers state that since the participants in this study had access to care they may be less likely to mistrust the healthcare system or fear that they won't get adequate care. The researchers also question whether the adequacy of the instruments, the sampling techniques or other factors could account for the differences. The researchers recommend further research to help understand the diverse health beliefs of multiethnic patients.

Synthesis of the Literature

Overall, the literature reveals that African-Americans claim to have less knowledge of advance directives and/or were less likely to correctly define the term than whites (Caralis et al., 1993; McKinley et al., 1996; Morrison et al., 1998; Morrison et al., 1998; Morrison et al., 1998; Murphy et al., 1996; Perkins et al., 2002; Waters, 2001). African-Americans were more likely to think that advance directives or living wills were estate wills (testamentary) (Caralis et al., 1993; Perkins et al., 2002). Participants in the Phipps et al. (2003) study did not cite lack of knowledge as a reason for not completing advance directives. Caralis et al. (1993) reports that African-Americans were significantly more likely to have learned about advance directives from their physician

even though overall patients are more likely to learn about advance directives from the media or other sources.

Throughout the literature African-Americans were far less likely to have written a living will or a durable power of attorney for healthcare than whites (Caralis et al., 1993; Eleazer et al., 1996; Gerst & Burr, 2008; McKinley et al., 1996; Murphy et al., 1996; Perkins et al., 2002; Phipps et al., 2003). Completion of a durable power of attorney for health care (DPOA-HC) gives authorization for someone to have access to a person's personal health information and to make decisions for them if they are unable to speak. A DPOA-HC is also called a healthcare proxy and gives authorization to a surrogate decision maker. If no document exists to authorize a decision maker, a legal next of kin becomes the proxy or surrogate decision maker. Often a patient will select among their next of kin for a particular person to make decisions, without completing a document, and this is also called a proxy.

A living will is a document that outlines a person's preferences for care (usually life sustaining such as CPR, ventilator or tube feeding), if they are unable to speak. The terms living will and durable power of attorney for health care taken together are usually called an advance directive or advance care plan but this is not consistent throughout the literature. Caralis et al. (1993) includes the selection of a health-care proxy or surrogate as completion of an advance directive and therefore reports an overall completion rate of 42% with African-Americans completing them at 46% and whites completing them at 45%. This far exceeds the completion rates of any other research reports. Of those in the

Caralis study that did not have an advance directive, African-Americans (46%) were more than twice as likely to not have, or want to name, a proxy as whites (22%).

African-American's attitudes toward the value of having their preferences known were similar to whites, that is, they value autonomous decision-making (Phipps et al., 2003). Their reluctance to sign advance directives is presumed to be related to mistrust, distrust, or some other factor of their cultural value system but this is not clear (Caralis et al., 1993; McKinley et al., 1996; Murphy et al., 1996; Perkins et al., 2002; Phipps et al., 2003; Shrank et al., 2005).

Morrison et al. (1998) was the only study that, after controlling for other variables, did not find that "proxy" completion was significantly affected by ethnicity. However, they also tended to use the terms advance directive and healthcare proxy interchangeably so it is not clear whether they were referring to a living will, durable power of attorney for healthcare, a family proxy/surrogate decision maker, or some combination of these directives. Investigators of other research that does not report the completion of a proxy alone as completion of an advance directive, report completion rates of zero to about 34%.

In the literature, it is documented that African-Americans were more likely to have discussed their wishes with their family (Perkins et al., 2002) but not with their providers (McKinley et al., 1996; Perkins et al., 2002). Gerst and Burr (2008) found that more white (56%) than black (36%) participants discussed end-of-life preferences with others. McKinley et al. (1996) found that 78% of whites had shared their wishes for life sustaining treatment with their families while only 37% of blacks had this discussion.

Morrison et al. (1998) found little difference between African-Americans (88%) and whites (92%), both were very comfortable talking about end-of-life care and wanted to discuss their preferences with their physician (whites 81%, African-American 71%). After controlling for other variables they found no differences related to ethnicity. Phipps (2003) studied patients and their caregivers and found that overall agreement of patient and caregiver on preferences for treatment when in near-death situations was no better than chance. However, African-Americans were well matched on desire for resuscitation (73% patient, 71% caregiver).

While African-Americans were willing to share their feelings with their families, they did not believe they should communicate their wishes with their physicians or put them in writing until they were very sick (McKinley et al., 1996; Perkins et al., 2002; Phipps et al., 2003). African-Americans tended to believe that talking to their family about their wishes was sufficient and this was not explored further in any of the research. However, all of these studies were done before the increase in the enforcement of the Health Information Portability and Accountability Act (HIPAA) (McClendon, 2010). HIPAA demands that a patients' personal health information not be shared with anyone who is not legally entitled to the information (Health and Human Services, Office of Civil Rights, 2003).

African-Americans tended to believe that they would not get the same amount and quality of care as whites, and they were not trustful of the healthcare system in general (Caralis et al., 1993; Eleazer et al., 1996; Gerst & Burr, 2008; Perkins et al., 2002; Shrank et al., 2005). More African-Americans than whites want life sustaining treatment when

terminally ill, no matter how poor the predicted outcomes (Caralis et al., 1993; Eleazer et al., 1996; McKinley et al., 1996; Phipps et al., 2003).

Morrison et al. (1998) were unable to find ethnic or cultural differences in their study but when most researchers controlled for socio-demographic factors, religion and other variables, there was still a significant difference attributed to culture or ethnicity (Caralis et al., 1993; Eleazer et al., 1996; McKinley et al., 1996; Murphy et al., 1996; Perkins et al., 2002; Phipps et al., 2003). Most researchers recommended further research to gain more insight into the impact of ethnicity on knowledge, perceptions and completion of advance directives, and discussion of advance care planning.

Summary of Literature Review

African-Americans report having less knowledge of advance directives than whites and are less likely to be able to define the term. Only one study reported that lack of knowledge was not a factor in the low completion rates of advance directives. African-Americans are far less likely to have completed a written advance directive or identified a healthcare proxy in writing. When there is nothing in writing, the legal next of kin becomes the decision maker. African-Americans are more likely than whites to have *kinship networks* that do not meet the criteria for legal next of kin in accordance with the Health Information Portability and Accountability Act (HIPAA). Disagreements among legal next of kin can lead to dilemmas over decisions such as seen in the Terri Schiavo case.

African-Americans value of having their wishes known is presumed to be on par with whites. They tend to discuss their wishes with their family and/or friends,

particularly when they are very ill but this is not clear and it was not explored further in any of the studies. The reluctance of African-Americans to sign an advance directive is presumed to be related to mistrust, distrust, or some other cultural or ethnic value.

African-Americans want more aggressive end-of-life care even in the face of suffering and extremely poor predicted outcomes. This is presumed to be because of health disparities and the presumption that they would not be offered the same amount and quality of care as majority populations. Nearly all studies recommend further study to gain more insight into the impact of culture and ethnicity on advance care planning.

The general public's knowledge about advance care planning, privacy rules and the relationship of chronic illness to end stage disease is lacking. This knowledge gap as it relates to African-Americans is much greater than for the white majority and believed to be even greater among African-American seniors. Changing health care practices such as specialists, hospitalists and reorganization of health plans have significant impact on patient-provider relationships. These relationships are believed to affect compliance and trust in provider recommendations. More information is needed about African-American seniors' perspectives about these relationships, advance care planning, and critical health care decision making.

There is little guidance for health professionals working with African-American seniors about how to approach them with discussions about advance care planning and end-of-life decision making. Health professionals need more insight into the issues that interfere with having these discussions and the actual writing of advance directives with this population. Methods to help health professionals assist African-American seniors and

their families to make critical healthcare decisions need to be identified. Therefore the present study was designed in an effort to fill these gaps.

Restatement of Study Purpose

The primary purpose of this study is to explore African-American senior's (aged 60 years and older) views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives. A secondary purpose is to use a virtue ethics approach as a model for conducting this community-based participatory research and to explore whether this virtue ethics and community-based participatory approach could create transparency and trust within the community with regards to the research. Thirdly, this research proposes to identify useful strategies for practitioners who wish to engage African-American seniors in deliberation and writing of advance care plans.

Significance of Research

It is hoped that findings of this research can be used to help nurses and other health professionals gain skill and understanding of ethical and cultural concerns when addressing advance care planning with African-American seniors. It is also hoped that findings will help nurses and other healthcare professionals to improve their skill and competence in working with African-American seniors about advance care planning, end-of-life decision-making, discussing and writing advance directives. It is further hoped that this research will serve to improve the experience of the process of advance care planning for African-American seniors, their family and friends and involved healthcare professionals.

Research Questions. The specific questions of this research are:

The research question is: What are the views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives among senior members of one selected urban African-American community?

The focus group questions are: Opening – Tell me a little something about yourself; Introduction – What made you decide to attend this group today?; Transition – What do you think are African-Americans beliefs, values and views about discussing who would speak for them if they were unable to speak for themselves in a critical healthcare situation?; Key– Why do you think African-Americans are less likely to write advance directives or do advance care planning?; and Ending– What should providers know to help them have this discussion with African-American seniors?

Chapter 3: Methodology

This chapter presents the methods used in seeking to answer the research question regarding African-Americans seniors' perspectives on advance care planning and writing advance directives. The design, the targeted sample and setting, measures, research procedures, and methods of data analysis are presented in detail.

Design

This study employed qualitative methods in conducting community-based participatory research (CBPR) to gather the thoughts and perspectives of a non-random convenience sample of urban-dwelling, senior African-American participants on the topic of advance care planning. A community advisory board was involved in the planning, design, and implementation of the research as well as the analysis of the data. A PowerPoint on Advance Care Planning was presented. After the PowerPoint presentations, focus groups were held. Content analysis of focus group data was used to identify and characterize the attitudes, perspectives, knowledge and preferences of African-American seniors related to this topic.

PowerPoint presentations. To introduce the topic and the study, the researcher showed a PowerPoint presentation on the topic of advance care planning (see Appendix A, PowerPoint). Information, professional experiences and stories about dilemmas were shared with attendees (see Appendix B, sample stories). The researcher was identified as a registered nurse, a PhD candidate at the University of Minnesota, and a Scholar of the Minnesota Hartford Center of Geriatric Nursing Excellence. The presentation was clearly identified as part of the research for completion of the PhD dissertation. Advance care

planning was defined as what professionals call “end-of-life planning.” More specifically, the question of this research was explained as an effort to understand the views and perspectives of African-American seniors about having discussions about “who would speak for them if they were very sick and unable to speak for themselves” and writing advance directives. It was further explained that advance care planning requires identifying personal values, cultural and spiritual strengths and having discussions with family, loved ones and healthcare providers about wishes for healthcare treatments. Potential participants were advised that knowing when one could need someone to speak is not predictable but is especially important to consider when one has an end-stage-disease. End-stage-disease was defined as “a progressive disease for which there is no cure” and the attendees were asked to identify some of these diseases. It was important to identify hypertension, diabetes and heart disease as end-stage-diseases because these diseases are so common among African-American seniors that they might not recognize them as “incurable” and thus end-stage-diseases. The importance of understanding diagnoses and prognoses as they related to informed consent was also discussed.

The importance of understanding that there are laws regarding “legal next of kin” and knowing who your legal next of kin is was discussed. A brief introduction to the Health Information Portability and Accountability Act (HIPAA) was given. The need to identify a trusted person to speak for you, particularly if you would prefer someone who is not your legal next of kin or a particular relative to speak for you, and the importance of talking to your family and whomever your chosen decision maker is about your wishes was presented. The fact that healthcare decision making is complex, difficult and stressful

for individuals, and more so for families when they don't know your wishes was also presented and discussed. The Terri Schiavo case and its controversy were briefly discussed as well.

The attendees were informed that the literature reveals that African-Americans are least likely to write advance care plans and were told that the key research question was "Why do you think African-Americans are less likely to write advance directives or do advance care planning?" They were invited to participate in a focus group and told that they would receive a \$25.00 gift certificate as a token of appreciation for their participation.

Attendees at presentations received a copy of the Planning Toolkit for the Minnesota Healthcare Directive (Stum & University of Minnesota Extension Service, 2008) (see Appendix C, AD Toolkit). They were also offered the opportunity to purchase (for \$3.00) a copy of the book, "The African-American spiritual and ethical guide to end-of-life care: What y'all gon' do with me? (Let's talk about it)" (Anderson, 2006) and were told that they would receive a free copy if they participated in the focus group. One or two reference copies of this book were left at each facility where a presentation only was done.

Community-based participatory research (CBPR). As previously described in the background section, community-based participatory research is a process whereby the structure and work of research is mutually envisioned, planned, implemented and disseminated in the context of a partnership between the researcher and the community. CBPR stems from the "participatory" research paradigm which challenges the positivist

view of science, knowledge and the roles of researcher and community participants. There are various forms of participatory research with different terms to describe them in different disciplines. CBPR is the term used in healthcare research to describe the shared power, reality, and connectedness between subjectivity and objectivity. In CBPR community members are not seen as objects to be studied but rather as Paulo Freire viewed them: as “subjects of their own experience and inquiry” (Wallerstein & Duran, 2003, p. 30). CBPR is not a methodology but an orientation to how research is conducted. The University of Minnesota Clinical and Translational Sciences Institute (2011) has issued guidance on conducting community research. This statement identifies the principles for community-based participatory research and these principles are consistent with the principles used in conducting this research. An advisory board comprising respected persons or leaders of a community is an essential element of this form of research.

Community advisory board. A community advisory board was sought to create an equitable collaboration between the researcher and the community. Community-based participatory research and the critical theory – constructivism paradigms require this equality. Wilson (2008), states that there should be a level playing field with the opportunity to exchange honest input and feedback. The researcher has been involved with these seniors in social and community activities for over three years. During that time the researcher gained the trust and respect of the group in general. Before the research was proposed, the researcher sought advisory board members among the group of seniors who had shown interest in the subject and had the following characteristics:

Active in several subgroups, believed the research was important for the community, able to articulate feelings and concerns; comfortable expressing opinions, willing to introduce researcher and research to various community groups, willing and able to read proposal and to meet to discuss input, willing to commit to support the project for about 18 months.

Four African-American community dwelling seniors agreed to act as advisors to this project. These seniors were chosen for their insight, knowledge, leadership, connections, and trusted positions in this African-American senior community. Their age range was 63-83 years. They had varied backgrounds, incomes, educational levels, and religious affiliations (see Appendix D for their biographical sketches and letters of support). More importantly, the advisory board chose the researcher. Researchers and the dominant society are generally suspect in this community so the researcher had to assure the advisory board that the motives for conducting this research in the community were sincere. Even though the researcher is African-American and had been immersed in this community for several years, it was important to assure the advisory board that the research had significance for the wellbeing of the community. The researcher had to gain the trust of these advisors and insure them that the community would be represented in a respectful and non-judgmental way. There was also some general distrust of the University to overcome. The University is associated with the dominant culture and the history of research conducted on African-Americans as noted by Washington (2006). Also, again Tuskegee was on the forefront (see page 11). An African-American nurse,

Eunice Rivers, kept the men in that study for 40 years (see Tuskegee Nurse, pp. 11-14) and for many she is seen as a Judas.

According to the literature, African-Americans desiring to conduct research in the African-American community can be more suspect than white researchers (Bullock et al., 2005). For this research the researcher initiated the research question, but the advisory board helped develop and refine the questions and the approach. Initially, the researcher wanted to educate the community about the value of having an advance directive and determine if they completed one after receiving this education. After consulting with the advisory board, the researcher realized that this approach was not consistent with the world views of the researcher or the targeted participants. It was not as important to have participants execute an advance directive as to find out their perspectives about why African-American seniors were reluctant to complete or even discuss them. The advisory board was involved in the entire process from design and methodology to analysis of data, and has agreed to participate in dissemination of findings. Other community advisors were consulted informally. The researcher found that the seniors participating in the presentations and focus groups were more comfortable when an advisory board member was present, so one or two of them attended most of the presentations and focus groups.

Focus group questioning route. The development of the focus group questioning route was taken from Krueger and Casey (2009). In a group setting, questions that might take just a few minutes to answer individually can spark comments from other participants and the resulting discussion can take much longer. Questions for this

research were designed and phrased so that they achieved the purpose of the research and generated group discussion.

According to Krueger and Casey (2009) questions should evoke conversation, be straight-forward, clear, short, and usually open-ended. It is also important to have questions that participants would not be embarrassed to answer or feel were inappropriate. To insure that the environment was conducive to honest answers, the researcher advised the participants that the aim was to find a collective answer to the questions rather than a personal answer. That is, “what do you think is the reason African-Americans...” rather than “what is your reason for ...” which provided participants the opportunity to make comments without disclosing information about themselves or their family if they felt it was too personal.

Krueger and Casey (2009) recommend categories for a questioning route that provides for flow of the discussion. The categories for this questioning route are: opening, introductory, transition, key, and ending question. The questions were developed by the researcher with the guidance and assistance of the advisory board. (Krueger & Casey, 2009)

The focus group questions were as follows:

- Opening – Tell me a little something about yourself (your name, age, how long you have lived in the twin cities, if you have family here – take about one or two minutes).

- Introduction – What made you decide to attend this group today? (It was explained that it is often difficult to recruit for research so it was of particular interest what made them decide to attend).
- Transition – What do you think are African-Americans beliefs, values and views about discussing who would speak for them if they were unable to speak for themselves in a critical healthcare situation?
- Key – Why do you think African-Americans are less likely to write advance directives or do advance care planning? (explained that this is in the event they are unable to speak for themselves in a healthcare situation and not necessarily their death)
- Ending – What should providers know to help them have this discussion with African-American seniors?
- Anything Else – Is there anything else you think I should know from you?

Participants. African-American seniors living in one urban Midwestern metropolitan area were the targeted participants of this research. The researcher defined African-Americans as persons of African descent who were descendants of slaves in the United States. No recent immigrants from the African continent were included. Age 60 years, rather than the Medicare 65 years of age for seniors was selected because African-Americans have a slightly shorter life expectancy than the general population. All participants were English-speaking, stated they are able to consent for their healthcare, completed a survey, and signed the consent.

Setting. Initially, it was planned to hold most focus groups at community centers and senior living complexes. The advisory board recommended these settings because of their cross section of seniors with various social status, income, education, health and activity levels. The advisory board felt that these would be excellent sites to do informational presentations and suggested that if more sites were needed, we could include professional and church groups. The researcher was unable to arrange to do presentations or conduct focus groups at any senior living complexes. After consulting with the advisory board, and given the time constraints, the nine focus groups were held at three community centers, two churches and two homes. Lunch was provided.

Recruiting and sampling. Over 250 recruitment flyers were distributed by the researcher at various senior events over a two-month period. The flyer clearly explicated that the presentations were to inform the community about advance care planning and recruit research participants. The flyer was titled “Who would speak for you if you were very sick and unable to speak for yourself?” (See Appendix F, recruitment flyer). The flyers only yielded one inquiry, which was from a church senior social group. Several inquiries for electronic copies of the flyer to share with colleagues and constituents were received from nurse or social work professionals but none yielded any participants. Two personal friends of the researcher arranged for presentations to senior groups at their church, both yielded focus groups. The advisory board recommended presentations at senior community centers and an American Association of Retired Persons (AARP) meeting; several presentations and focus groups were conducted as a result. The researcher presented to the staff of a large health and wellness center in North

Minneapolis and the director recommended the presentation to an affiliated senior group. The leader of this senior group was instrumental in getting several participants to attend presentations and focus groups. Another personal acquaintance made arrangements with her mother to hold a presentation and focus group at her home.

The originally targeted number of participants was a minimum of 30 with 50 participants desired. Four months were allotted for the recruitment and conduction of the research. The advisory board recommended doing the presentations to large groups and then to have four to six persons per focus group. The advisory board said that it would be easier for the seniors to engage and speak in groups this size. However, it was difficult to get people signed up for focus groups at the time of the presentation. The advisory board recommended that dates be set up for focus groups in advance so that the seniors could choose a date that worked with their schedule. They suggested morning and afternoon options but suggested that focus groups end at least an hour before dark so seniors wouldn't have to drive in the dark. When scheduling groups of four or five, the researcher found that some participants did not show up. Sometimes this was because they became ill or didn't feel well but sometimes they forgot or didn't show for some unknown reason. This was a problem because arrangements had been made (space, lunch, etc.), and people who might have wanted that time were not given the option.

The advisory board recommended scheduling one or two extra people if they wanted a particular day and telephone reminders the day before the scheduled group. This resulted in nine focus groups with numbers of participants varying from two to 12 (group participant numbers in the nine focus groups were 6, 2, 3, 5, 12, 8, 4, 6, and 6). Potential

participants were advised that transportation money was available if they needed it.

Transportation money was not offered if they were just riding together but was offered if someone had to drive to pick someone up.

Measures

Demographic survey with stimulus questions. The three-page self-administered demographic and personal data survey and stimulus questionnaire with 54 items were created by the researcher and piloted once with eight seniors at a presentation (see Appendix E, questionnaire). Many questions and the testing methodology were modified but were not re-piloted. The questions were constructed as a result of reviewing the literature and have face validity for the researcher and community advisory board. Data from this questionnaire were aimed at obtaining basic demographic and personal information, and stimulating thought prior to engaging in the focus group. The tool was administered after participants signed informed consent but prior to participation in the focus group. The one-page evaluation questionnaire was administered after the focus group was completed. This final 14-item evaluative questionnaire comprised questions related to the participants' interest in, opinions about, and response to their focus group participation. These questions had 4 potential responses ranging from 1-4 with a don't know/not sure option. An "other comments" field was available so that participants could choose to comment in an open-ended written format (see Appendix E, page 4). Statistics presented are generally descriptive and are not intended to be inferential. Survey items are described below.

Current age. A senior was identified as an individual age 60 years and older rather than the Medicare age of 65 because African-Americans have a lower life expectancy than white Americans. Participants were asked to write in their current age.

Life expectancy. “How many years do you THINK you might live,” was asked because the literature reveals that procrastination is an obstacle to writing an advance directive. The options were 0-5; 6-10; 11-15; 16-20; 21-25; and more than 25. The highest number was added to the current age to calculate their self-selected life expectancy in years and for the more than 25 option, 30 years were added to the current age. This question was intended to encourage the participants to think about how much time they might have to consider the question of advance care planning; and to have them think about the possibility and inevitability of their own demise. Some literature suggests that older and sicker people might be more likely to consider engaging in discussions about end-of-life decision-making (Morrison et al., 1998), other literature suggests that the likelihood of discussing end-of-life planning decreases with age (Gerst & Burr, 2008). (Gerst & Burr, 2008; Morrison et al., 1998)(Gerst & Burr, 2008; Morrison et al., 1998)

Identify as African-American. The participants were asked if they “identified as African-American” because some black people could be considered African-American (descendants of African slaves in the United States) but were descendants of other African cultures such as Afro-Caribbean or other race. African born immigrants were not included in this research. This is important because other black races might have different perspectives (McKinley et al., 1996).

Health insurance. The literature states that some African-Americans believe that they do not need to have an advance care plan because they believe that whether or not they have good health insurance determines their fate in the healthcare system. Stimulus questions related to this notion are: “I believe I will get good care in the hospital if I have health insurance;” and “I believe the healthcare system will serve me well if I am very sick even if I don’t have health insurance.”

Attended the presentation. It was expected that most participants would attend the presentation on one day and the focus group on another day. This question was aimed at finding out how long it had been since the participant had attended the presentation.

Relationship with the provider. The literature states that some patients want their doctor to make decisions for them, implying that they think that their doctor knows them well and/or what is best; their doctor encourages them to participate in decisions; or their doctors will solicit information from them to make decisions (Levinson, Kao, Kuby, & Thisted, 2005). Questions to elicit thought about this notion were: “I trust that my provider has my best interest in mind when making healthcare decisions about me;” “My healthcare providers ask for and encourage my input when planning my care;” “I want my healthcare providers to make all of the decisions about my health and tell me what to do;” “My healthcare providers really listen to me and spends enough time with me to address all of my concerns;” “My healthcare providers explain all of the options of my treatment in a way that I can understand;” and “I believe that my healthcare providers would know what I want done if I was hospitalized and unable to speak for myself.”

As healthcare plans change, patients and doctors move about and healthcare providers may change. Many healthcare facilities have “hospitalist” that see patients when they are hospitalized. These are physicians who might not be familiar with the patient or their history beyond their medical records. Also, many patients see several specialists. Questions to elicit thought about this issue are: “I do not see the same healthcare providers most of the time” and “When I go to the hospital I don’t see my usual healthcare providers.”

Previous knowledge about advance directives and advance care planning.

Throughout the literature reviewed, African-Americans tended to have less knowledge about advance directives than whites (Kwak & Haley, 2005). There was a brief definition of living will and durable power of attorney with questions to elicit previous knowledge about advance directives. There were also questions to elicit whether the participant had written or considered writing an advance directive or had even had a discussion with anyone about their wishes. There was a question to direct the participant to distinguish between an advance directive and an “Estate Will” or a “Last Will and Testament.” Sometimes people who have written a will for their estate would have completed an advance directive at the same time. However, it is important that advance directives be discussed with family and healthcare providers and be made available to them before a crisis occurs. If the participant stated they had written an advance directive, they were asked if a copy was in their medical records, if they had discussed their wishes with their family, and, if appropriate, family members have a copy.

Whether writing an advance directive is considered might be related to whether a person believes it is important to have their wishes followed or believe having an advance directive will insure that their wishes are followed. To elicit thought about this, the yes/no question, “Having an advance directive will improve the chances that my wishes are followed if I am very sick and unable to speak for myself” was asked.

Legal next of kin, HIPAA and privacy. According to the literature, African-Americans are more likely than white Americans to state that their family will make decisions for them. However, African-Americans are more likely than white Americans to have a kinship network that is broadly defined as “family” (Chatters, Taylor, & Jayakody, 1994; Dennis & Neese, 2000; Waters, 2001). They are also less likely to have identified a surrogate/proxy decision-maker in writing (Eleazer et al., 1996). Recent changes and increased enforcement of privacy rules may affect previously held ideas about family decision makers (McClendon, 2010). Also, there is a tendency to believe that if a person wants a particular family member or friend to speak for him or her that the chosen person’s decisions will prevail. To elicit thought and discussion about these issues, the following yes/no questions were asked: “I know who my legal next of kin is;” “I would be satisfied with my legal next of kin making decisions for me;” “My family and friends know what I would want to have done if I was very sick and unable to speak for myself;” and, “I have a person to speak for me if I am unable to speak for myself and my family knows who that person is even though I don’t have it written anywhere.”

Prior experience with critical healthcare decision making. Other questions were asked to elicit thought about previous experience with end-of-life situations and

situations where critical healthcare decisions had to be made. Examples of these questions are: “Do you have any of the following medical problems;” “I have been in the hospital or the emergency room in the past two years;” In the past five years “I have been so sick that my family and friends thought I was going to die;” “I have been on ‘life support’ machines before;” “Someone close to me has been on ‘life support’ and, died;” and “Someone close to me has been on ‘life support’ and did not die.”

Income, religion, education and geographic location. Income level, religion, educational background, and geographic location are listed as confounders or covariates to end-of-life decision-making throughout the literature (Eleazer et al., 1996; Gerst & Burr, 2008; Hanchate, Kronman, Young-Yu, Ash, & Emanuel, 2009; Murphy et al., 1996). Income level was not solicited in this research because it is difficult to ascertain how the amount of income relates to the person’s perception of adequacy of the income. Also, income is considered very personal for many people and asking the question was judged to be potentially offensive to participants. Religious affiliation was also not solicited. The relationship of religion and spirituality is difficult to decipher, and it is difficult to determine the relationship of religion or spirituality to perceptions. The researcher and the advisory board felt that religion or spirituality would best be dealt with as it came up in the focus groups. Educational background was included because it was believed to be more straightforward and might give some insight into the method or approach to the discussion and if education had influence on who participated in the research. The researcher was aware that people who attended the presentations might have graduate degrees or less than high school education with variable employment and

economic success in their lives. The question, “What kind of work have you done most of your life?” was aimed at eliciting insight into this matter. Geographical location was not asked but all participants were from the Twin Cities metropolitan area.

Evaluation survey. At the end of the focus group the participants were asked to complete a 14 question evaluation using a 4-point Likert-type scale that ranged from from “1” [strongly agree] to “4” [strongly disagree]; “9” was an option for don’t know/not sure (see Appendix E, questionnaire pg. 4). Examples of questions include: “I found the focus group discussion very interesting;” “The focus group leader was not clear;” “I don’t think we should talk about things like this in the community;” and, “I learned a lot by participating in this focus group.” There were several lines for open-ended comments.

Procedures. After Institutional Review Board (IRB) approval was obtained, flyers (see Appendix F, flyers) were circulated to community center day programs, parks, a senior boat ride activity and several community activities frequented by seniors. Key community leaders were engaged to assist in the identification of centers, senior activities, and other strategies for access. There was follow-up with all expressions of interest. Meetings were scheduled in the centers, churches, homes and senior activities/meetings identified. Once potential participants or leaders agreed to the informational sessions, the investigator prepared the facility for their arrival and the showing of the PowerPoint on advance directives. After the session, potential participants who met inclusion criteria were invited to attend a follow-up focus group to discuss their views about African-American seniors and advance care planning. Most presentations

were done on the same day as the focus groups. The consent process, and all protocol procedures that were approved by the Institutional Review Board, were followed throughout the conduct of this work.

Human subjects considerations. The study protocol received expedited review and approval by the Human Subjects Committee of the University of Minnesota without stipulations (see Appendix G, IRB approval).

Consent process. The original plan was to put the consent on PowerPoint and read it to the participants but this was too time-consuming since most of the presentations and focus groups were done on the same day (see Appendix H, consent). When presentations were done separately from focus groups, a consent form was given to anyone who said they were interested in participating in a focus group later. When presentation and focus group was done on the same day, the participants were given the consent immediately upon arrival (before presentation) and there was usually 15-20 minute wait for everyone to arrive. There were also 30 to 40 minutes between the presentation and the focus group for lunch. The participants were asked to review the consent during that time. There was an advisory board member at most of the presentations and focus groups to assist anyone needing assistance with reading or writing. Before the focus group began, the participants were asked if they had any questions about the consent. Any questions were answered and the consent was signed before the group began.

Data collection procedures. After the consent was signed by individuals who desired to participate, a demographic survey and stimulus questionnaire (Appendix E,

questionnaire) was distributed and completed by participants. The survey and questionnaire engaged participants in the content and primed them for the focus groups.

The focus group was started after all of the participant's questions were answered. Focus groups started with introductions; participants were asked to share their experience and knowledge of advanced directives. After this, the focus group questions were asked in order. The dialogue was audio taped using digital recording equipment for later transcription. Focus groups lasted between 66 and 100 minutes. They were ended after participants responded to the question, "What should providers know to help them have this discussion with African-American seniors?" and "Is there anything else you think I should know from you."

The focus group recordings were transcribed by a transcriber who used *NVivo 8* qualitative software (QSR International Pty Ltd, 2008). Thereafter they were reviewed and verified for accuracy. The researcher edited the tapes and removed identifying data. Data remained confidential until identifying data were removed from the document. The focus group transcriptions were reviewed by the investigator, the Cultural Wellness Center knowledge production staff, and members of the Community Advisory Board in the conduct of the analysis.

Analysis. The data from the nine focus groups were reviewed in type-written textual form by four community advisors, two knowledge production staff at the Cultural Wellness Center (CWC), and the researcher.

NVivo Coding Step 1. The researcher coded the data with *NVivo 8* qualitative data analysis software (2008) by highlighting text data and assigning it to a "free node"

(see Appendix I, NVivo). Free nodes were created and text references added until all of the transcripts were gone through. There was considerable overlap and data was put in more than one free node. The themes initially identified (e.g., fear, trust, lack of knowledge, etc.) were related directly to writing an advance directive, but there were also significant data related to the African-American historical experience in the United States that was not captured. A second review of the data was conducted with the aim of adding any themes even if they did not appear directly related to advance care planning. This second review of the data revealed that many themes were related to the historical African-American experience in the United States. Even though these themes did not appear to be directly related to advance care planning or writing advance directives, it appeared that they were responsive to the research question “What are the views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives among senior members of one selected urban African-American community?” Themes related to deracination (cultural uprooting), loss of community and culture, past discrimination and others, repeatedly appeared throughout the responses of the focus groups and thus are included (see Appendix I, NVivo Coding Step 1).

CWC Coding Step 2. The Cultural Wellness Center (CWC) knowledge production staff consisted of two staff with extensive experience analyzing focus group type data from cultural communities. They have no formal training in healthcare or end-of-life decision-making. The “CWC has a long history of engaging community residents to improve health through self-study, surfacing and producing knowledge, cross cultural

knowledge exchange, and relationship building” (Allina Health Systems & Cultural Wellness Center, 2010). Two CWC knowledge production staff reviewed the transcript data independently and identified relevant data from the text. Those data were assigned themes which were collapsed under “major themes” (see Appendix J, CWC Coding Step 2). The researcher met with the CWC staff and discussed the combining and collapsing of the themes.

Collapsed Themes Step 3. The researcher renamed and collapsed the themes into 30 themes (see Appendix K, Collapsed Themes Step 3). One participant reviewed these themes with the results section of the dissertation and gave verbal input. The results section and themes were then reviewed with a PhD nurses with expertise in end-of-life qualitative research. These 30 themes were then sent to the advisory board along with the results section of the dissertation which showed the quotes the researcher had selected to represent them. The advisory board was asked to review the quotes and the themes and think about how they should be collapsed into categories.

Advisory Board Meeting Notes Step 4. The researcher divided the themes into six named and four un-named categories to begin with (see Appendix L, Advisory Board Meeting Notes Step 4). The researcher had a four hour luncheon meeting with the advisory board, the agenda was as follows: Review what you think about themes identified; review what you think about quotes (too many, relevance, etc.); discussion of what does all this mean?; are these findings in keeping with the intent of the research AND respecting the community? There was much discussion and 11 categories were agreed upon. The advisory board thought that there should be primary categories that

were directly related to writing advance directives and secondary categories which were underlying influences to the primary categories. They also thought that some of the themes should be listed under more than one category. The 30 themes were re-arranged under the 11 categories; five were primary and six were secondary (see Appendix L, meeting notes, themes agreed upon by researcher and advisory board). These themes were then organized in order of significance in response to the research question. This categorization was based on a consensus of the researcher and the advisory board about which were most important and directly related to writing advance directives, and which were related to underlying influences.

In addition to the focus group data, the personal information data, stimulus questionnaire responses, and the evaluation survey were entered, summarized and subjected to descriptive statistics. These were organized in tabular form for presentation and dissemination.

The next chapter, Chapter 4, presents the findings of the research. The demographic, personal information, stimulus question responses and the evaluation questionnaire data are summarized. Themes from the focus group analyses are also presented.

Chapter 4: Results

This chapter presents the findings of the research. First, the basic demographic information gathered from the participants is presented. Following this, the information gathered via the demographic survey, stimulus questionnaire, and evaluation are summarized. Finally, the themes that were derived from the data gathered from the focus groups are presented.

Demographic and Personal Data

In response to a question about the complexity of the questionnaire, 90% of participants responded “disagree” or “strongly disagree” to the question on the evaluation: “This form was too complicated to fill out.” However, some of the answer formats appeared complex and the researcher had to interpret intent. Example: After answering Likert-type questions with 1=strongly agree, participant marked yes/no questions with a “1.” The researcher interpreted this as a “yes” answer.

There were 52 participants, 45 females and 7 males, aged 59 to 92 years; they lived in an urban setting, in Minneapolis and St. Paul (Twin Cities), Minnesota. In response to the yes/no question, “Do you identify yourself as African-American” one participant scratched out “American” in “African-American” and wrote “Blk,” one participant did not answer the question, one participant answered No and one participant answered No and wrote in Jamaican-Cuban. In response to the yes/no question of whether they had health insurance, five participants over age 65 responded No, two participants under age 65 responded No, and one participant did not answer the insurance

question. It is presumed that all participants over the age of 65 qualify and receive Medicare. The reasons for the No answers were not clear.

Age and life expectancy. The participants' ages were distributed between 59 and 92 years with a mean 69; median 74; mode 69. (see Table 1, ages). Four participants did not answer the question regarding age and one participant put greater than 65. Of the four participants who did not give an age, two selected life expectancy of 11-15 and 16-20 years. Six participants did not select a life expectancy. Forty-five participants chose the number of years they thought they might live. Of those, 40% thought that they would live more than 25 years. Life expectancy in years could be calculated for 45 (86%) of the participants (Table 2). The distribution of life expectancy ages was 72 to 122 years; mean 88.8, median 91, mode 91 (Table 3). Twenty-eight (65%) estimated their life expectancy in years to be about 90 or more.

Educational background and usual work. Four participants did not answer the education question. Some participants checked several answers such as "completed high school," "technical school," and "some college." When this happened, only the highest education level was recorded. Five participants did not complete high school. Seven participants completed high school only. One participant listed technical school only and three listed some college and technical school. Nineteen participants listed some college and six participants listed two years of college. Six participants listed four year degrees and four listed graduate degrees. No participant had a terminal degree.

Table 1

Age of Participants (N=47)

Age	59	61	62	64	65	66	67	68	69	70	72	74	75	77	78	79	80	81	83	84	87	91	92
N=47	1	6	1	1	1	1	3	1	4	3	3	3	3	2	3	1	1	2	1	1	1	1	1

Table 2

Self-estimated years of life expectancy of sample

Estimated Life Expectancy in Years	N=45 (%) [86% of total sample]
0-5	2 (4%)
6-10	4 (9%)
11-15	8 (18%)
16-20	8 (18%)
21-25	5 (11%)
>25 (added 30 years)	18 (40%)

Table 3

Self-estimated age calculation of life expectancy of sample (N=43)

LE	72	76	77	79	81	82	85	86	87	88	89	90	91	92	93	94	95	98	99	100	103	104	105	107	122
N=43	1	1	1	1	1	1	2	2	2	1	2	1	4	2	2	2	2	2	3	3	1	1	2	2	1

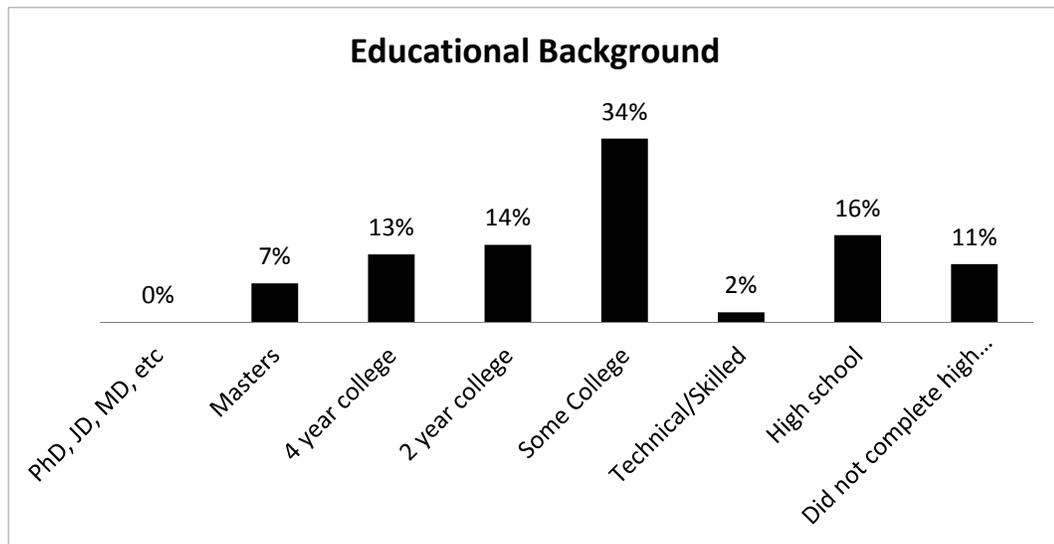


Figure 1. Educational background of participants (N=52)

A question was included for participants to describe the kind of work they had done most of their lives. Responses for those with graduate degrees were: Educator, RN/social worker, writing/editing, and management/consulting. Responses for those with four year degrees were: social worker, business, teacher, RN, paralegal, and life of service. Those responding that they had two years of college listed the following usual jobs: social work, clerk/administrative assistant, secretary, aerospace technology/chef, pre-K teacher/child care, and civil rights/mediation. Responses for those listing technical/skilled labor certification, with or without “some college” were: Cement mason, social service, cosmetology, and data entry. Of those who responded that they had “some college,” five listed education, school or teacher aid; four listed office/clerical; one listed nurse/key punch/foster and day care; one each listed social service, corrections officer, nursing/medical assistant, and supervisor. One participant selecting “some college” did not list any usual work. Of those who listed “high school” as their highest grade completed, three did not list any usual work, two listed office/clerical and one wrote

“lot.” For those that checked that they did not complete high school, three did not list any usual work, one listed “labor” and one listed child care. Four participants did not answer this question.

Medical problems. Participants were asked to indicate any medical problems that they had from a list of 12 conditions; a response item was left for them to fill in “other.” Three participants did not complete this section of the form. The top five conditions reported were hypertension (n=33), arthritis (n=28), diabetes (n=17), heart disease (n=16) and stress (n=15). They were also asked for their height in inches and weight. Twenty-six participants responded to this item but none put height in inches only. Seven participants identified themselves as obese and gave their height and weight, three identified as obese but did not list their height and weight, four listed height and weight which was obviously obese but did not check the obese item. Two reported cancer but only one identified the kind (breast). “Other” conditions reported were degenerative joint disease (n=1), hernia (n=1), vertigo (n=1), multiple sclerosis (n=1) and cholesterol (n=2). The frequency of responses is presented in Figure 2.

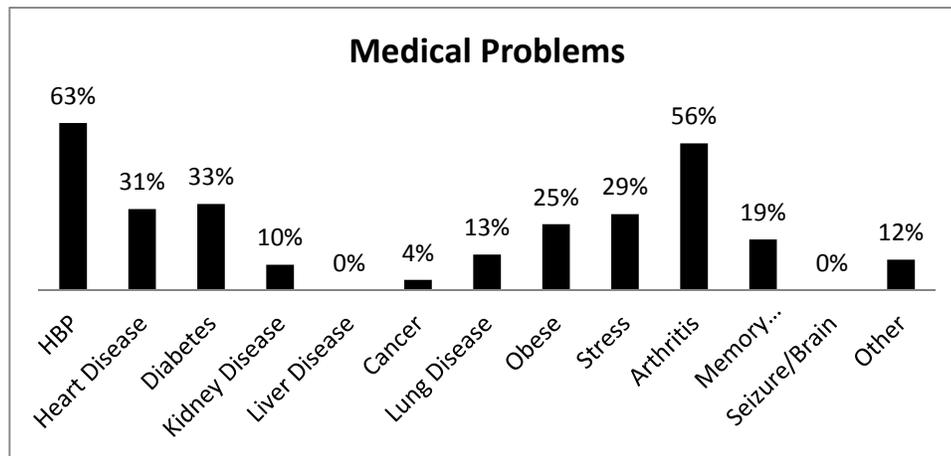


Figure 2. Medical problems (N=52)

Participants were also asked to indicate (yes or no) whether they had attended a presentation about advance care planning, and, if so, when. In this sample, 18 (35%) stated they attended today; 6 (12%) stated they attended one week ago; 6 (12%) stated they attended 2 weeks ago; one each stated they attended three and four weeks ago; 7 (13%) stated they attended but did not state when; 6 (12%) stated they did not attend; 1 reported attending twice; and 6 (12%) did not answer the question. Actually, all of the participants attended a presentation, those that stated they did not attend one, attended one on the day of the focus group.

Stimulus Questionnaire Responses

The stimulus questions followed the background and personal data survey section of the questionnaire. The stimulus questionnaire was completed by 52 (100%) of the participants, but all of them did not answer all of the questions. The first section (items A-K) was aimed at stimulating thought about healthcare providers and the healthcare system in general. The second section (items 1-16) were aimed at stimulating thought

about personal knowledge about advance care planning, privacy laws, and experience with critical health situations involving self and/or others.

Healthcare and healthcare providers, items A-K. The responses to items A through K, “Thinking about the healthcare provider you usually see, how much do you agree or disagree with the following statements” were made on a 4-point scale, with an option of don’t know/not sure. The findings are presented in Table 4, items A-K. These items were aimed at stimulating thought about the quality of illness care with and without insurance; trust in the healthcare system; if participants have felt encouraged by providers to participate in their healthcare decision making; if they believe their providers should make decisions for them; and the kind of relationship they have with their providers. Over 60% of the participants agreed or strongly agreed with questions A, C, D, E, H, and I. Three percent did not answer questions A – G, 6% did not answer question H and 17% did not answer question I. Over 60% disagreed or strongly disagreed with questions F and G. Answers for question B were split with 23% answering don’t know/not sure. Questions J and K were split with about 30% answering don’t know/not sure or not answering the question at all.

Table 4

Stimulus Questionnaire - Items A-K, Views Related to Healthcare/Healthcare Providers (N=52)

Item	1-Strongly Agree n (%)	2-Agree n (%)	3-Disagree n (%)	4-Strongly Disagree n (%)	9-Don't know/Not Answer	No Answer	Mode
A. I believe that I will get good care in the hospital if I have health insurance.	20 (38%)	24 (46%)	3 (6%)	0	3 (6%)	2 (3%)	2
B. I believe the healthcare system will serve me well if I am very sick even if I don't have health insurance.	7 (13%)	13 (25%)	13 (25%)	5 (10%)	12 (23%)	2 (3%)	2
C. I trust that my healthcare providers have my best interests in mind when making healthcare decisions about me.	11 (21%)	25 (48%)	6 (12%)	3 (6%)	5 (10%)	2 (3%)	2
D. My healthcare providers encourages me to participate in decisions about my health.	13 (25%)	29 (56%)	5 (10%)	2 (3%)	1 (2%)	2 (3%)	2
E. My healthcare providers asks for and encourages my input when planning my care.	14 (27%)	29 (56%)	6 (12%)	1 (2%)	0	2 (3%)	2
F. I want my healthcare providers to make all of the decisions about my health and tell me what to do.	3 (6%)	7 (13%)	23 (44%)	15 (29%)	2 (3%)	2 (3%)	3

Table 4 (continued)

Items A-K: Healthcare/Healthcare Providers (N=52)

Item	1-Strongly Agree n (%)	2-Agree n (%)	3-Disagree n (%)	4-Strongly Disagree n (%)	9-Don't know/Not Answer	No Answer	Mode
G. I do not see the same healthcare providers most of the time.	4 (8%)	11 (21%)	18 (35%)	14 (27%)	3 (6%)	2 (3%)	3
H. My healthcare providers really listen to me and spends enough time with me to address all of my concerns.	14 (27%)	27 (52%)	6 (12%)	1 (2%)	1 (2%)	3 (6%)	2
I. My healthcare providers explain all of the options of my treatment in a way that I can understand.	14 (27%)	23 (44%)	5 (10%)	0	1 (2%)	9 (17%)	2
J. I believe that my healthcare providers would know what I want done if I was hospitalized and unable to speak for myself.	3 (6%)	14 (27%)	14 (27%)	6 (12%)	4 (8%)	11 (21%)	2
K. When I go to the hospital I don't see my usual health care providers.	9 (17%)	12 (23%)	9 (17%)	6 (12%)	6 (12%)	10 (19%)	2

Knowledge/next of kin/experience, items 1-16. The next set of questions required yes/no responses with the option of “0” for I don’t know. The first 12 questions were intended to stimulate thought related to knowledge and beliefs about advance directives, legal next of kin, and who would speak for you if you were unable to speak for yourself. Questions 13 through 16 were aimed at stimulating thought about experience with end-of-life situations with self or others. Overall, the testing method was probably not always clear or too complex. The researcher or advisory board member answered questions that the participants had but some of the questions still had conflicting answers. At times the answers are presented as the researcher understood the participant’s intent. For example, if the researcher marked “1” by the “yes/no” question it was counted as yes since in the previous set of questions “1” was “strongly agree.” While statistics are given they are not intended to be inferential. The statistics are only intended to be generally descriptive of this sample and are offered in support of the qualitative data. Some of the questions and the answer format were piloted with the first group of presentation participants only. No validity and reliability statistics were calculated for the questionnaire since the questions were primarily intended to stimulate the focus group discussion. The questions were determined to have face validity by the researcher (based on the literature), and the community advisory board.

Of the 16 participants who answered, “yes, I had an advance directive,” only about half had a copy in their medical record; however 81% had discussed their wishes with their family and 63% had given appropriate family members a copy. Those that had written an advance directive tended to have written them as part of completing a

testamentary or estate will. Questions 2 – 6 were not to be answered if the answer to question 1 was yes. It appears that this was not always clear. Question 2 was a poorly written yes/no question. Most participants knew who their next of kin was and would be satisfied with them making their decisions (question 7 and 8). Question 11 was intended to stimulate thought about whether the next of kin would know what the participant's wishes were. Question 12 was aimed at stimulating thought about conflicts that might arise between next of kin but probably fell short of that goal. Questions 9 and 10 were designed to stimulate thought about personal illness and how emergencies can happen quickly. Questions 13-16 were aimed at stimulating thought about critical healthcare decisions the participant might have had for themselves or been closely associated with. (See Table 5, Items 1-16).

Table 5

Responses to Stimulus Questionnaire Items 1-16: Knowledge/Next of Kin/Experience (N=52)

Items 1-16	Yes n (%)	No n (%)	“0” n (%)	No Answer n (%)
1. I have written an advance directive. (If yes, please answer a, b, & c then skip to question 7)	16 (31%)	25 (48%)	0	11 (21%)
a. A copy is in my medical records.....	7/16 (44%)	8 (50%)		
b. I discussed my wishes with my family	13/16 (81%)	3 (19%)		
c. Appropriate family members have a copy	10/16 (63%)	5 (31%)		1 (6%)
2. I have never heard of an advance directive, a living will or a durable power of attorney before the presentation or before today. (If YES, go to question 7; if NO [you HAVE heard of advance directives before], please answer all remaining questions)	15	14		
3. An advance directive is the same as an Estate Will or Last Will and Testament. (What will be done with you and your things when you die.)	6	20		
4. Have you considered writing an advanced directive?	23 (44%)	8 (15%)		
5. Have you ever had a discussion with anyone about writing an advance directive or living will?	23 (44%)	8 (15%)		

Table 5 (continued)

Items 1-16: Knowledge/Next of Kin/Experience (N=52)

Item 1-16	Yes n (%)	No n (%)	“0” n (%)	No Answer n (%)
6. Having an advance directive will improve the chances that my wishes are followed if I am very sick and unable to speak for myself.	28 (54%)	2		
7. I know who my legal next of kin is. (If NO, skip to question 9)	39 (75%)	5 (10%)		8 (15%)
8. I would be satisfied with my legal next of kin making decisions for me.	40 (77%)	4	1	7
9. I have been in the hospital for more than two days in the past 2 years.....	17 (35%)	28 (56%)		4 (8%)
10. I have been to the emergency room more than once in the past two years.....	17 (33%)	31 (60%)		4 (8%)
11. My family and friends know what I would want to have done if I was very sick and unable to speak for myself.	31 (60%)	14 (27%)	3	4 (8%)
12. I have a person to speak for my if I am unable to speak for myself and my family knows who that person is even though I don't have it written anywhere.	39 (75%)	8 (15%)		5 (10%)

Table 5 (continued)

Items 1-16: Knowledge/Next of Kin/Experience (N=52)

Item 1-16	Yes n (%)	No n (%)	“0” n (%)	No Answer n (%)
13. I have been so sick that my family and friends thought I was going to die.....	9 (17%)	37 (70%)		6 (12%)
14. I have been on “life support” machines before.....	2	44 (85%)		6 (12%)
15. Someone close to me has been on “life support” and died.....	12 (23%)	32 (58%)	1	7 (13%)
16. Someone close to me has been on “life support” and did not die.....	10 (19%)	34 (65%)	2	6 (12%)

Evaluation responses. The last page of the questionnaire (see Appendix E, page 4) was an evaluation titled: “About the Focus Group Today... Answer at the END of the Focus Group.” The question was “How much do you agree or disagree with the following statements about this focus group?” Responses were made on a 4-point scale with an option of “don’t know/not sure” and “other comments.” The response frequencies are shown in Table 6 and comments are recorded in Table 7.

The evaluation was aimed at finding out whether the participants found the topic interesting and helpful and if they learned anything by participating. It was also aimed at getting the participant’s perception of the clarity and appropriateness of the focus group process and the discussion of the topic. Most questions had agreement (A, B, H, I, J, and L) or disagreement (D, E, F, G, K, M, and N). Only question C, “There was too much information to discuss in the short time” had split responses.

Table 6

Response Frequencies for Evaluation of Focus Groups (N=52)

Item	Strongly Agree n (%)	Agree n (%)	Disagree n (%)	Strongly Disagree n (%)	Don't know/ Not sure	No Answer	Mode
A. I found the focus group discussion very interesting	42 (81%)	8 (15%)	0	0	0	2 (4%)	1
B. The focus group helped me to think more about advance care planning	38 (73%)	11 (21%)	0	1 (2%)	0	2 (4%)	1
C. There was too much information to discuss in the short time	7 (13%)	20 (38%)	15 (29%)	7 (13%)	0	3 (6%)	2
D. The focus group leader was not clear	4 (8%)	2 (4%)	17 (33%)	25 (48%)	0	4 (8%)	4
E. I didn't like talking about this subject	5 (10%)	5 (10%)	17 (33%)	23 (44%)	1 (2%)	1 (2%)	4
F. The focus group leader did not allow enough time for us to talk.....	2 (4%)	2 (4%)	15 (29%)	29 (56%)	1 (2%)	3 (6%)	4
G. I really did not understand what the focus group was about.....	2 (4%)	2 (4%)	21 (40%)	24 (46%)	0	3 (6%)	4
H. I would like more information about this Subject.....	16 (31%)	25 (48%)	3 (6%)	4 (8%)	1 (2%)	3 (8%)	2
I. I think this is a good topic	40 (77%)	10 (19%)	0	0	0	2 (4%)	1

Table 6 (continued)

Response Frequencies for Evaluation of Focus Group (N=52)

Item	Strongly Agree n (%)	Agree n (%)	Disagree n (%)	Strongly Disagree n (%)	Don't know/ Not sure	No Answer	Mode
J. I would like to see more discussions like this	31 (60%)	15 (29%)	0	0	2 (4%)	4 (8%)	1
K. I don't think we should talk about things like this in the community	3 (6%)	4 (8%)	15 (29%)	28 (54%)	0	2 (4%)	4
L. I learned a lot by participating in this focus group	32 (62%)	16 (31%)	1 (2%)	1 (2%)	0	2 (4%)	1
M. This form is too complicated to fill out....	2 (4%)	1 (2%)	14 (27%)	33 (63%)	0	2 (4%)	4
N. This subject is too personal to talk about in public	2 (4%)	1 (2%)	14 (27%)	31 (60%)	1 (2%)	3 (6%)	4

The open comments section was aimed at eliciting any comments participants might have about the focus group in an open text format. All of the comments were very complimentary of the researcher and the process. All comments are noted in Table 7.

Table 7

Comments on Focus Group Evaluations

Comments on focus group evaluation:
The group leader was excellent.
Wonderful study, loved it!
Some method should be devised to make this topic required – educators, more community discussion or group leaders, etc.
Very good presentation. Everyone seemed very comfortable speaking on this subject.
I feel the presenter did an excellent job and made a touchy subject very interesting and informative.
Very good speaker. I will now because of this discussion I will have one done.
I would like to see this questionnaire in depth promoted in the newspaper, hopefully to attract more people to become involved. Spokesman, Insight News.
I would like to attend more meeting like this. (wrote name, address and phone number)
Considering subject matter and the demographic of panelist, Sandra was an excellent facilitator and very good at trying to keep us on track and focused.
The letters and numbers made it confusing for me. Great job of focusing the discussion.
Good topic. Enjoyed the subject.
This was very educational for me. I intend to educate my family and be more educated myself.
I enjoy the group section today
It is inf [sic] I learn about group. I enjoyed the group. I learned more about this program
No comments

Comments on focus group evaluation:

Ms. Crump was well prepared, informative, culturally aware & interesting. I plan to have a discussion with my family members. Thank you.

Our focus group leader was very educated on this topic; presented it in a way for all of us to understand and we left with the positive attitude and desire to share this with family and friends.

Oh! So educational

The focus group was very helpful to me. Thank you so much

Very good – more time needed

Very well done – wish you much success with this project

Fear of dying is cause for refusal of this discussion.

A wonderful teacher who made sure we understood the meaning of Advance Care Planning. Our sisters and brothers need more of these meetings.

Very interesting & needed

I really enjoyed this group. I rec'd a lot of good info – Thanks.

Knowledge Generated from Focus Group Discussions

The themes are noted in **bold** print below and quotes are used to support them. Parentheses inside quotes represent other participants talking in the background. Brackets inside the quotes add context or explanation. The knowledge produced is also responsive to the focus group questions and aims about recruitment and what providers need to know to have discussions with African-American seniors regarding this topic. Responses related to these questions as well as examples of verification and clarification quotes of the researcher and the advisory board members during the focus group are included. Some quotes of participants who made suggestions and had ideas for solutions are also included, along with some quotes from participants who have completed advance

directives and those that are considering completing them as a result of participating in this research. Examples of quotes thanking the researcher were also included.

Table 8

Primary and Secondary Categories with Themes

Primary Categories with Themes

1. Trust Issues
 - Family
 - Healthcare providers
 - HC system in general
 2. Fear
 - Of death
 - Of talking about death
 - Signing is like signing death certificate
 - Death is final
 - Self-fulfilling prophecy
 3. Relationships
 - Burdensome
 - Difficulty choosing among family members
 - Trust issues
 - Communication issues
 - Privacy and secrecy
 4. Lack of information/knowledge
 - HIPAA
 - Trust issues
 5. Procrastination
 - Denial
 - Excuses
-

Secondary Categories with Themes

1. Deracination
 - Slavery
 - Integration
 - Loss of culture/community
2. Deterioration of family/community
 - Assimilation

- Society is youth oriented
 - Decreased reverence for seniors
3. Past Discrimination
 - Lack of sense of empowerment
 - Government owes them
 - Lack of resources
 4. Experience
 - Caregiver/decision maker
 - Death/funeral
 5. Self-fulfilling Prophecy
 - Affirm the positive
 - Don't speak the negative into existence
 6. Religion
 - Just pray about it
 - God will decide
-

Primary categories with themes

Primary 1—trust. Participants talked about **lack of trust** and the many ways it manifests itself in families, the healthcare system and society in general. They talked about Tuskegee and other healthcare atrocities.

Quote 1: And who can I trust. Who would do because of the relationships. And this stuff is real. You know a lot of us as African-American people, the first thing you will hear them say is (emphasis) "ooh my family, we are so close, we are real close, we are this, we're that." OK, now y'all know I am telling the truth but when you really open up the book and really look in that book, and REALLY look in that book, it ain't necessarily so. OhhKay!

Quote 2: And it's the trust. And since we are in this building you can see, its still here, the trust is still lacking. Because it was so much fight about this building [University of Minnesota Urban Research and Outreach Center – UROC] because the people, African-Americans were afraid that they were going to get here and they were going to experiment on our children and that. Because, in their history they have had this happen. So even the building was quite a deal in our community (group agreement, I remember that).

Quote 3: Every since when they were testing those men, Tuskegee (yeah) I think black people lost a lot of trust (group agreement).

Quote 4: Or like years ago when the girls were pregnant, what was it the state or county decided they were going to give them a hysterectomy without letting the child or parent or anyone know. (oh really). Yeah, that was back in... there was a time when young women down south, a lot of them can't have children because they had given them a hysterectomy without their permission (oh I didn't hear that).

Quote 5: Can I say also, a lot of African-American people, a lot of this trust goes back to this syphilis thing that they had (group: oh yeah, yeah, etc.) where they were giving people the syphilis, that stuff still remains in some of our minds when we go to the doctor.

Quote 6: It's a fear. If I tell my children, its a fear, we are not sure how we are going to be treated. We don't trust the doctors because of our

history. I had an uncle that was blind because they deliberately gave him gonorrhea because they were having research about what gonorrhea would do to you in the later stages. So they experimented on several black soldiers, he happened to be one. His thing was he went blind but it takes years to do that and most people know that there was so much experimentation done until you are afraid. A lot of times we don't tell our children because we don't want that anger coming through them that came through us, (agreement). So there are lots of different things that we don't do as black Americans because of your experiences. And one of the main things, like you said before is because of our lack of knowledge. (yes, that's a biggie).

Quote 7: Well the new one is the HIV and the penumonia (and swine flu). You are giving me that vaccine and it takes them back to that syphilis thing. Even though I take them, I am talking about our people. It takes them back to that syphilis thing. Yes we do have trust issues and it is legit for us, it might not be to them.

Quote 8: But like you said about the insurance. I am divorced after 36 years and when I had my husband's insurance and another insurance, they were taking real good care of me but now, its like "what you want now?" I mean it, like being rich and then you get treated differently. When I had coverage, they were very nice to me. Sent me to the Mayo Clinic.

Primary 2—fear. They talked about **fear of death** and **fear of talking about death**. Several participants talked about feeling like **death is so final** and how the idea of **signing an advance directive feels like signing your own death certificate**.

Quote 1: We got this from our parents. Death is a scary thing, to think about it. I have a hard time with it. Deciding who is going to do what. That's too final for me.

Quote 2: I also think that it is about this is final. That is mostly what it is for me. I can talk about it better than I can sit down and do what I need to do. I have a problem of sitting down and filling this out because it is final. I got to leave here [die].

Quote 3: I know that part of the reason that I tinker around with end of life wishes is like you are issuing, you are stating, hey, this is final. You know, death is final and it's like you feel like you are signing your death certificate when you do it. But then once you do it and you are still around, you know that you haven't signed your death certificate; you have just gotten things ready for it...

Quote 4: I think oftentimes in the African-American community, to discuss death or the directive or the different things we fill out around dying, it's like you are kind of signing your own death certificate. We don't like to speak of death, in general. So it is something that we fear, if we fill it out and have to start dealing with this information it is like we are kind of writing our own death certificate.

Quote 5: You know death in the black community has always been something scary. It has been a scary thing. And we have a different kind of concept on death. I think a lot of it comes from our religious upbringing and some of the things that have been passed down to us that make us so fearful of it because it is so final to us. We don't like to think of anyone we love as being, this is final.

Quote 6: We don't want to do it because we don't understand. Like my husband, he thought that if he signed that it was like signing his death certificate. That's why we need more programs like this to help us to understand.

Quote 7: ...So I am just saying, it is passed down through generations, you just don't talk about death, that's what it was with us. But this is a new generation and we just don't, like I said we learn...

Primary 3—relationships. They talked about **relationships** and how thinking about advance care planning and who would speak for you require you to analyze your relationships and how painful that can be. They talk about how choosing one family member rather than another could cause discord in the family. They said that trust among family members deteriorates, sometimes due to general discord, but is often fueled by having “more, better or other” options and obligations. They talked about **communication** and difficulty talking to family about these issues.

Quote 1: ...It gets kind of personal and I started weighing my relationships with people. My own family. And it is painful, its damn,

pardon me, damn painful. (Inaudible group agreement) Did I open up a can? [can of worms, stuff no one wants to talk about]

Quote 2: We don't talk to each other. We should but we don't talk to each other. I mean we should but we don't know what the other person is thinking or feeling because we don't say anything. I know when I was a little girl my dad would say, don't tell people your business. And you don't tell things outside of your house. So where do you go to get information, you are afraid to ask.

Quote 3: Sometime if we talk about stuff like this to our children they will avoid you because they think you are being too needy. ... When I talk about stuff like this my kids avoid me and now when they call or I talk to them and they say "mom, how are you?" I say [cheerfully] "just fine, how are you." And they come over and I don't talk needy. I mean what we are talking about is who would speak for you. My daughter will say, "mom, you're not that old so why are you talking like that?" So now I just keep it to pleasantries. So when she comes by she might say, "mom I'm busy, I have children, I don't have time to call you or come by." So I will say [cheerfully] "oh that's fine" and then when I see her, "ooh hi, its so nice to see you." You have got to keep it pleasantries or they feel that you are needy. (group agreement and laughter).

Quote 4: [a 75 year old female who has completed an AD but has it in her bank box] I have really been thinking about end of life things

quite a bit for the past 7 or 8 years. Not because I have had any serious health problems but I do have some health problems. I only have one child left and he is a kind of child that, even though he is an adult and very capable adult, he carries his heart in his hands and he has every since he came into this world. And he doesn't deal well with death, dying, illness, anything. I mean, he just comes completely apart. We have talked about that many times. So for his sake and my own sake, I thought I am going to have everything written out. One of the reasons I want to have everything written out is because I have a very strong willed family member and it is either her way or the highway and she has this way of twisting around things so that it ends up her way. I can see her entering the picture and him saying, "you know, I think mom would like it this way or that way" and she would say, "I don't think that's the way it should be done," and he would say, "well Ok." He doesn't like confrontation. So that is one of the reasons why I am even down to the point where I am going to plan out my funeral service just the way I want it. The big problem I have now is that I have wanted to talk to him about these things and he says, "mom, I don't want to talk about it today." So I have got to, I do have a brother that does not live here so that he can kind of help him... I have 5 siblings that are all younger than me, I am next to the oldest and they have all left us [died]. I thought some of them would be around to help bury me.

Quote 5: I have a daughter, my son lives in Minnesota; he is married and got a family. But when he came to the hospital, he didn't want to see his mother in the hospital. He is so used to seeing me active so I think that he didn't want that responsibility, even if I explain it to him like you explained it. My oldest daughter who lives in Chicago seems to be a very reasonable person and she seems to be fair about it and able to explain to them and say "yes mother and OK, I'll speak for you" because I am going to tell her what I want and she is going to explain to them. She is like a good mediator whereas my other daughter, sometimes I think she thinks I am crazy, so.

Quote 6: I have 3 daughters living, I have lost two kids. My son that I lost would have probably been the one that I would have wanted to speak for me. But the other 3 girls, one is very hyper, one is too sentimental about me, I would never. But I have a daughter that is the manager of a bank and then she is very religious so I am going to make her to speak for me if anything happens to me because I know that first of all she will pray about it and the decision that she gets, the other two will follow her, and I trust her.

Quote 7: For someone who worked in the healthcare for so many years [clerk in health clinic for 32 years, retired] and I was there when they talked about the directives and I don't have one but I know my children, especially the oldest one, she is the mouthpiece and she would

talk for me. And I think my husband would too but my daughter can out-talk him.

They talked about **privacy and secrecy** and how you don't talk about your "business." Adults didn't talk to their children of any age about their personal affairs, and how that was passed down. A book, *The Grace of Silence* written by one of the advisory board members' nieces, Michele Norris (2010) speaks to this issue.

Quote 1: A lot of people, I think, think that it's too personal and they don't want to divulge it to anyone. It's nobody's business... A lot of that derives from our culture (group: that's right, your business is your own)

Quote 2: My feelings are that, from my own experience, like she said, we don't want to talk about anything that is not relevant to what's going on. We don't want our neighbors to know our business and so we don't talk about any intimate problems that we have. I know in my family we didn't talk about anything that went on in the family to outsiders. Even to your close relatives. I mean my mother and her sisters might talk but you didn't talk to the cousins and other people and you kept it to yourself.

Quote 3: One of my girlfriends had to go in for removing lumps in the uterus... She was like you [speaking to another participant], she had no family here. She did not have a living will written. She was very angry that they were making her fill out this living will to have someone speak for her in case [she needed it]. She was so angry, it was a process, she felt it invaded her privacy, she was very private, she didn't want to do it. She didn't see the need, I mean they

explained it to her and she understood that but she still felt that it was unnecessary for her to do. And so we had to sit and talk about that and so like you said she had to go to her friends because she tried her sisters. She has 11 sisters and brothers and nobody, and she has some retired sisters but they were not willing to come here for that time she needed them. So, she filtered through the friends, I was one of them, myself and another lady were the ones that she had to go through that process of getting the non family members on that directive which then made her more infuriated because she doesn't like things NOT to be the way she wants them to be... She finally did it but she felt invaded, that her privacy had been invaded and she was very angry about that process. And she just felt that it was personal and private information, information that nobody else needed to know.

Primary 4—lack of information and knowledge. They talked about **lack of information and/or knowledge**; and **lack of resources** (income, insurance, education, family and community support). Participants gave many examples of the effects of past discrimination on current relationships and decision making about advance care planning. They asked questions about where they should keep the documents and who should have copies. They started to think and talk about others in their family whom they might need to be concerned about because of **HIPAA** (Health Information Portability and Accountability) and next of kin issues.

Quote 1: Can you have more than one name on HIPAA?

Quote 2: [I have a] Question about next of kin. I have this granddaughter whose mother died when she was three. Now I was her legal guardian until I guess she turned 18. Now she is 21 and she lives with me. If she ends up in the hospital, who is her next of kin, me or her father, her father lives in Minneapolis. (group: her father). So then I can quit worrying about her.

Quote 3: I have a question about that. If you don't have a regular doctor. I mean, who do you give your form to?

Primary 5—procrastination. Some participants thought it was more a matter of **denial, procrastination,** or just **excuses,** than fear.

Quote 1: Sometimes I think it is just procrastination (group agreement).

Quote 2: I don't think that it is so much about being afraid. I think that they just don't want to deal with it. They are in denial.

Quote 3: I think even those of us, who are knowledgeable, it is not that we don't know, we are just, we put it off because we think we have this time, procrastination.

Quote 4: ...I know a little bit about the nurses and doctors and how they squabble sometimes. And I know a lot about HIPAA (laughter). I haven't talked to anybody about this health directive and I have had several nurses tell me that I should because I do have an illness that they haven't found a cure for, I have MS... Yes, that is one reason why I wanted

to come to this group, to see how this health directive thing does work. My husband would make the decisions but then he is so busy arguing. I guess I would let my son do it because my two daughters bicker among themselves...

Quote 5: You know I think we can come up with 101 different excuses, we all have them. And not only are they excuses but I think a lot of it is just not wanting to get to the problem and not wanting to face it head on. And that's not easy to do, it is difficult... I think what makes it difficult is just the fact that people are not aware of the necessity and importance of having that out there. To have that piece of paper or have that information on hand. I really don't think that we think that they are going to mess with my organs or they are going to do this or that. It is just the fact that we don't know as blacks we are just getting into the last 2 or 3 decades where we have had lawyers and we have had people explaining that you need to have a will because you have this and that. It's just now that we need a will because we have something to leave our kids. Separating the two I think one of the problems get to that position we don't know how to separate the difference between the will and what you are sharing with us today.

Quote 6: I heard you talk about the directive and I was in the hospital last year and they asked me and I have just been putting it off, I need the directive and my situation has changed.

Quote 7: ... I have often read about this but I haven't done anything about the information that I have read. I know that it is important and the older I get, the more I think about it, when am I going to do this? So I thought well maybe this will inspire me to take that next step and seriously think about what's involved. Because one never knows and I should have someone to speak for me.

Secondary categories with themes

Secondary 1—Deracination (to remove one from their native environment; to pull up by the roots).

Loss of culture and community was a historical theme of much of the discussion in the focus groups. Participants talked about **slavery...**

Quote 1: I think that it is a carryover from slavery. Because you are in the NOW syndrome all of the time. You don't really plan for a future because you can't really count on a future, and you just stay in that now syndrome. And if you can make it with 3 squares that day, Ok then you will worry about tomorrow, tomorrow morning.

Quote 2: Culturally we have relied on a central figure in the family, matriach or patriach. We went to that person to find out information and make decisions. Then it was delegated to the brainiest or most spiritual person in the family... based on what would Jesus want or how would that fit in with the scriptures. This comes up from slavery, we

only had so many decisions that we could make, massa made the decisions...

Quote 3: I think you had a good point when you started talking but we don't have that spiritual thinking in our families no more. Our families have deteriorated so badly so there is no Big Mama or Captain Jack.

Participants talked about how there were positive and negative effects of **integration** and while they appreciated many of the positive effects, they recognized that negative effects such as urban renewal and gentrification had many devastating effects on the African-American community. They talked about how African-Americans took care of their ill family members out of necessity; there were no nursing homes for them to go to, even hospitals were for rich people. Also families were interdependent because they had limited incomes and education and were dependent on hard local work. They lived near each other and when there wasn't sufficient family to provide care, the church and neighbors pitched in and acted like family. They formed kinship networks. They also talked about seniors not wanting to **burden** their children with their problems. They talked about more women began working outside the home thereby decreasing the availability of caregivers.

Quote 1: Well, the old folks said intergration was going to help and hurt and I think it did.

Quote 2: We are so spread out now. We used to live together out of necessity.

Quote 3: ...I think integration because we were allowed to move. I mean when I grew up we were redlined so you couldn't really leave your little circle... Then the freeways came through and that messed up St Paul because St Paul had a [black] society. They had beautiful homes, doctors and lawyers... I just think when you lose your community, busing and so forth... they have just melt[ed] us down to nothing; there is no black community.

Quote 4: I mean if you think about it, long time ago when folks got sick, they didn't, I don't remember hearing so much about folks going to nursing home, we didn't have no nursing home. When folks got sick, they were at home until they died... so they stayed at home until they died. Little kids brought them water. Everybody took care of that person. We didn't have no nursing homes and hospitals were for rich people.

Secondary 2—deterioration of family/community. They talked about conflicts that arise when trying to maintain culture and community while aspiring toward the individualistic goals of the dominant society; and the expectation of having more “things” (consumerism). They talked about the **deterioration of the family** due to negative and positive effects of **assimilation into the dominant culture**.

They talked about the black church being located in the community and being a training ground for leaders. Participants also talked about how upper class and middle class blacks lived in the same communities with lower socioeconomic status (SES) blacks

before integration. They were role models and children had goals to be like them. After integration upper and middle class blacks tended to distance themselves from lower SES blacks; they moved away and were thought of as thinking and acting like white folks. Because youth associated them with white people, their goal to be like them was not seen as attainable. This has had a detrimental effect on generations.

Quote 1: ...I have 16 sisters and brothers. I grew up on a farm so I picked 200 lbs of cotton every day, chopped cotton from sun up to sun down for \$6 a day. I left home and went to the city, I was still a country girl, but I was afraid to come back home because I was scared that I would have to go back to the field. (laughter). So I stayed away...

Quote 2: You know, when I had cancer three years ago I learned a lot. Because I called some of my family members, and I had money in the bank at that time where I could afford to send them a round trip ticket to come up here and just be with me while I go through chemo. I went through the chemo, the radiation, all of that. I have been through hell and back. I recall one sibling telling me, "well I got a job." Well so what. You know those kinds of things. You mean you have got other things that are more important than me. So therefore, it makes me think and it makes me pull away and say who do I have to speak for me. The only person I have is Jesus, you know.

Quote 3: You just don't know in the African-American community about things like this. My father wouldn't even go to the hospital or the

clinic to have himself checked. My brother would have to just insist and take him. So surely he wouldn't have wanted to sign a form because its passed down through the generations, its just taken for granted that you are going to be taken care of...

Quote 4: I think that most of the seniors, African-Americans or blacks, are being pushed to be, to fend for themselves. Either they have to be put in a senior home or a rest home. They can't take care of themselves or the family is too busy to help them and they have to make the decision on their own as to where they are going to go or what they are going to do. So they feel like whatever happens to me, my family don't care and they don't need to know so I am going to keep this all within myself and then what happens, happens.

Quote 5: A lot of people feel so embarrassed to think that their kids aren't going to take care of them. These kids today, they might and they might not and it won't be because they don't want to, it's because the women have to work.

Quote 6: We have one in our building, exactly that, she don't want her kids to know [that she is ill], and she wouldn't even let us in. I went bamm on that door. When I don't see somebody that I should be seeing, I want to check to see how they are. She finally came to the door but she doesn't want her kids to know it. Then the manager couldn't tell it because she could have gotten in trouble. So the last thing that happened, so when

the last thing happened, we hadn't seen her so we had them to go in there to see and she was so sick that she couldn't move. Had to get the ambulance to take her out and now she is in a nursing home and I don't know if her kids know today. She has two girls and a boy but she don't want them to know.

Others talked about how it might be **burdensome** for person affected or family member to talk about advance care planning.

Quote 1: Not only that I remember my mother died many years ago of breast cancer and she didn't say anything. I said, "mama, why didn't you say anything" and she said "well I didn't want to worry anyone." (agreement that this is common). By then she had both breast removed and then went to her bones all because she didn't want to bother anybody.

Quote 2: Do you think that some part of that is denial? Plus the fact it is part of discussing that with your kids and parents, you feel like you don't want to burden them or approach them with that kind of stuff (group agreement).

They talked about our **society becoming more youth oriented** and having a **lack of reverence for elders**; and how this is inconsistent with black culture. They talked about children not being disciplined like they used to be so they don't respect elders and their teachings.

Quote 1: Sometimes my daughter gets mad she tell me she will move me to a nursing home and my niece told them, "don't do it."

Quote 2: You know, our generation, we looked up to our seniors.

We appreciated our seniors. This generation looks down to the youth.

They really think the youth, the teenagers, they cater to them...

Secondary 3—past discrimination. Issues related to **past discrimination** and the lingering effects of slavery and Jim Crow laws were discussed as contributing to African-American seniors' **lack of sense of empowerment**. This lack of sense of empowerment was manifested in the views and perceptions of many participants. It was expressed as low self-esteem; struggle to overcome meager beginnings or ongoing poverty; and lack of trust of the healthcare system and health practitioners.

Quote 1: I think as black people that we are afraid of different things. Because we have been taken for so many years and a lot of black people don't understand a lot of stuff because it was taken from us. And then when it did come out we have a hard time viewing it. You know, they are afraid if not of what it is, they are afraid you are trying to take them for something or they are afraid you are trying to get over with something.

Quote 2: ...I realized that I was talking to the doctor and she [well educated daughter] had a degree and he [acted] just like I wasn't saying anything and my daughter said, "Excuse me sir I believe my mother was talking to you" and he came back and everything changed. Its like if you don't have a high level of education they just ignore you. Then after that they were very attentive if I asked a question and would answer and explain.

Quote 3: You know a lot of African-Americans have been hurt and they done had so many failures so they are just trying to make it. They don't want to get involved in stuff, they are just trying to make it and live day by day.

They talked about how blacks, frustrated by the civil rights struggle, began to **feel like the government owes them** and should take care of them.

Quote 1: You know we are constantly talking about the 40 acres and a mule that we haven't gotten and a lot of us are still thinking that the government owes us and should take care of us.

Quote 2: ...You just kinda live day by day and let things go. Either you get on welfare and you are kind of stuck there, it's helpful and then it's not helpful. You're just torn between having a good time or just living day by day, doing what you wanna do and just really not taking care of business. But the more educated we are the more we learn about taking care of business and being responsible.

Secondary 4—experience. They talked about their **experience with the healthcare system** and how they used to be able to get information about their friends and family when they went to the hospital but how it is so much more difficult now. Many of them knew this to be the result of HIPAA (Health Information Portability and Accountability Act), others did not. Some liked the tightening of the privacy rules and others didn't. Others had heard about end-of-life dilemmas in the media.

Quote 1: ...like I told you, when I came out of surgery my so called girlfriend was making fun and telling me "girl you all messed up" telling me about my surgery. The doctor was confiding in her thinking that she was suppose to have this knowledge. [about HIPAA]... I am glad that has stopped because I am ready to sue.

Quote 2: I also have a situation where my girlfriend's husband died while she was out of town. And I had to be the one to relay information from the hospital to her but that was before HIPAA thank goodness. Because I was able to keep her up to date and stuff, letting her know how he was doing although he died before she got back. ...on the phone she had to tell them to tell me so that I could relate the information...

Quote 3: I just want to mention, my granddaughter was in college in Indiana and had a seizure and all of us are here. So of course we called to find out and the hospital would not give us any information. So I said that to say that we need to make sure that our young people have it written down somewhere if they are over 21.

Quote 4: I heard on the news, getting back to your point that it isn't necessarily about death, different ones wanted to get information about somebody they loved and they weren't related and they are not getting that information (and they are standing right there). Sometimes they don't get any information even though they know someone is in the

hospital and they might have taken them there. They say well sir we can't give you any information about the person you brought in (is that what they do, they don't give any information; weren't you the one that told us that?)

Quote 5: I also remember that little girl down in Florida [Terri Schiavo] and the trauma she went through, I followed that quite a bit.

Some participants had **experience as caregivers and/or decision maker for a family member or friend**. One participant talked about not understanding when her husband was asked to sign an advance directive when he went into hospice care.

Quote 1: I am 92. ...My wife had Alzheimers and I took care of her at home for 10 years. So that started me thinking about the program that you are presenting. My youngest son is my next of kin as far as I am concerned, he will have my power of attorney. I have made out my wishes. My body will be donated to the UMN medical school. So when you ask the question why I am here, I just say, all of the above.

Quote 2: The one thing that I would like to speak on is, you were asking the question, "Why don't you think that African-Americans would do this." I will tell you an experience that I had, my husband was a lot older than I am and he passed away. But before he passed away, the people, and before he left the nursing home they kept at him, "we need you to sign this form." Well he didn't understand, he thought that if I sign this no matter what I won't get any help. So I said to him, "Honey go ahead

and sign it because you know what, I am going to do everything I can for you and if necessary I will" because he said if something happens to me I really want the people to come and help me. So he signed it just to come home and relieve them. So when he did pass, I did call the emergency people and the hospice nurse came at the time that it was happening. She said don't do that and they said m'am, if you want to help us you can and if you don't, leave the building. So she grabbed the thing and she started helping. I said this to say that he didn't understand so I think what we need to do is, like you said today, I think it is a very good thing when you said just because you are signing this it doesn't mean that you are saying that I am dying. It is just saying that if I go into a coma somebody has to say what to do. Even if it is a diabetic coma, its death threatening but you can come back from there... So I think if it was explained to us, because I have not signed one either. I talked to my daughter about it and the other two would listen to her. So thats the way I am going now but I am thinking about it because of what you said today. I can tell her, you know this does not mean that its the end of my life, I am just signing it to take some pressure off of you and the rest of the family. So I think that you did a very good presentation, it kind of opened my eyes.

Quote 3: I am a retired RN for more years than I want to talk about. I am 78 years old I have 9 children and it was, my husband died on 10/17 [2010, one month ago], and I was thinking when you were talking

the way we had to solve the problem. He had had a stroke years ago and I was his caretaker. But then the day that I had to call 911, while he was getting into the ambulance he was out over 5 min. By the time the time the firemen came it was another 5 min. By the time they got him in the hospital the doctor told me that they had resuscitated him right away again so it was 3 times that he had, so. But even knowing that, it was still difficult for me to make the decision because I knew that he wanted to live as long as he could and even with that stroke and the things that he went through he really enjoyed his life. So knowing that the brain damage, but even knowing that and the kids, we must have had 15 people in that room trying to make the decisions and I knew that, so my thing was at least I could see him. And that is not good thinking to me. So the kids were really good and I realize how wise they were in their thinking and how they waited for me to decide and they were very supportive so that was good. But it is hard to make that decision even when you know what should be made. You always feel, something with death, and when you have been with guilt you know the symptoms of how people feel after someone dies and they have to make the decisions. You get a guilt about anything even when you know its not so...

Quote 4: [In response to the statement that she had told doctors to “just keep her [86 year old mother] breathing” when she was critically ill during several hospital admissions – participant was asked if she thought

about the risk of her mother becoming a “vegetable” (term the group had used)] *No because, she was fighting. She was feeling really sick. She had been to ICU 3 times within 3 months. And each time she came back. So we just wanted to find out what was causing all of this and they finally did. They got some medications together and she was much better. But at the time, she was saying I don't want to be here this way. We said, "mama if you are willing to fight we are going to be here with you" and she kept saying take me and we took her back to emergency each time. We stopped taking her to the county hospital and we got into Emory and that's what saved her really. Because the guy at County told everybody to come home and that was a year ago. She is still alive, we had to lift her up out of bed and to the potty and everything but now she is able to get up on her own. She can go to church sometimes...*

...But this has made me think about what I should do for my only daughter. She [her mother] had 5 daughters and a son but I only have one daughter. My daughter has already said that she doesn't want to make that decision alone and I could use one of my sisters to help her. She has already said which sister she didn't want to help. (laughter). So it has made me more aware of what I should do to help her. But as far as my mom, now I don't know...

Literally every group talked about their **experience with death and funerals**.

They talked about their involvement in chaotic and well planned funerals. They talked

about deciding between burial and cremation. They talked about family and friends who did not have insurance and needed donations to be buried. They talked about how failure to make arrangements up front or to talk to someone about burials was often a privacy issue but then became everybody's business when the family had to solicit money for burial. The researcher made it clear to participants that the discussion was not about death and funerals. However, talking about death and funerals often led to good discussion about the value of prior planning.

Quote 1: But you know, they think that it's nobody's business but it ends up being everybody's business. Especially when they are pulling out a collection plate every time you sick.

Quote 2: And then my personal interest in it was personally that going through some deaths. When my dad died, it was total chaos. And I swore from that never again was I going to go through another family chaotic funeral. And I have been for a long time trying to get my mother to fill out (laughter from her mother) information and directives. So in the last five years we have accomplished that but that was a very long process that we have gone through in making that decision (more laughter from her mother and the group) and that those papers needed to be available to people but we have gotten that done.

Secondary 5—self-fulfilling prophecy. They talked about the importance of **positive affirmation** and saying what you want, and **not speaking the negative into existence.**

Quote 1: I think that fear of talking about death, like when I was coming up, if I talk about this it will happen.

Quote 2: I am just wondering if it is a holdover from the old days. Remember when we had policy writers and the numbers. (group remembers). It is sort of like if you start preparing for something it is going to happen, like if I don't do such and such, it is not going to happen.

Quote 3: I think [I will live] about 55 more years [to age 130] (group laughter). Yeah. Well you gotta want something before you get it, right. And I take care of myself so why should I leave and I keep on doing what I am doing. Even my doctor tells me that I am about the healthiest lady my age that she has, and she is a doctor.

Quote 4: I think its maybe fear. Fear of if you start planning for your death that you are going to die (agreement).

Quote 5: And don't be so negative. When I want to talk about if I get sick, then [family says] "oh you are so negative."

Secondary 6—religion. There was not much mention of **religion** as it directly related to advance care planning. However, some participants mentioned how religion might play into a decision to think about, discuss or write an advance directive.

Quote 1: [family member would not come from out of town to be with her when she had chemotherapy] ...So therefore, it makes me think and it makes me pull away and say who do I have to speak for me. The only person I have is Jesus, you know.

Quote 2: ...I have an incurable disease; I have COPD and all that goes with it. But I am of the belief that God is going to heal me.

Quote 3: At that time I didn't think about her being a vegetable. I didn't consider that she could become a vegetable. I didn't consider any of that... And she hadn't given us any other directions. One time when she was really sick, she said "I just don't want to be here this way" and I said, "well mom lets just pray and if God wills that you go then that will be His will." I felt a sense of calm about me but I was still looking for [her to get better] and she got better. I am glad that she didn't give up the fight but at the time I didn't think of her becoming a vegetable.

Quote 4: But church was very important but they didn't use those words, end of life, they didn't say those words. Oh no, that would have meant death, no matter how you tried to explain it. That would have been death, those words.

Quote 5: [recently made out a will with advance directive] ...I am satisfied, God is good to me and I am not worried about anything. When the Lord get ready for me I would just rather go to sleep (group: me too) and just leave this world. I don't want to go to no hospital and they be resuscitating and sticking that thing all down in my throat and trying to keep me alive, I don't want none of that.

Quote 6: I think most black people are very spiritual. They have religion, we believe in it, we believe in miracles but we also have to

believe in what we see and in what God is doing. You know if you see your somebody there and they don't have a directive and you are the one that has to make the decision, we have to consider not only what we think they would want but by their condition we have to consider what the chances are and if they are going to be able to live a life and not be a vegetable. We have to consider all of those things and religion comes in if we pray for them. But we also have to consider what's going on. And through knowledge, and I think this even helps in those cases even with religion. Because if they have a directive then you know what they want. If you know what they want then it is a different story. It is easier and makes it better. I knew my husband wouldn't want to be a vegetable so that helps you make your decision.

Advance directive already written. Some participants already have an advance directive, usually written when they wrote their will. Most said that they had them done at some kind of senior legal fair at one of the community senior centers. They talked about even if they made their wishes known, they don't know if their family would, or could, follow them. Even though some had written advance directives, often they had not discussed them with their family or practitioners and did not recognize them as being very important.

Quote 1: The way we got our directive done was when we had our first grandchild and she is almost 8 now. We decided that it was time to do a will and to do the directive as to what we wanted, what our wishes were,

what we wanted our family to know, when that time came. Especially based on the fact that we had no family here. So we were anxious to get that done. We found, I have taken it rather casually over the years, but I see now that it is not casual. It is extremely important and I think as we get older it is more meaningful. When your health is involved, about 4 1/2 years ago I was diagnosed with pulmonary fibrosis which is a lung disease. So when I was hospitalized for quite a while they were asking me all over the place, do you have a directive. Everywhere I went, from the hospital to a rehab center everybody wanted to know. This thing is not just something I am filling out, this is important. I am glad that I had this experience...

Quote 2: C and I both have directives done when we had our wills made. We had them done because I have children and he doesn't have any. I came to this meeting because I didn't have anything else to do. (laughter). Well she said tell the truth. I came to this meeting to see if you were offering something different than what we have in ours. I was in the hospital this year and had surgery. They all have copies, the doctors, hospital and they didn't seem to think that there was anything wrong with it.

Thinking about planning. (as a result of this research)

Quote 1: I was thinking that when you tell them that you don't want to be resuscitated, if they had to make up their minds and you didn't have

it written down someplace how would they do it? I guess they would say, "well that is what I would want done to me." And I am trying to think, would I feel the same way about them? I have a brother and a sister left. I really think that this gives you something to think about because you know how they are and you know their wishes, they probably wouldn't leave it to you, they would probably leave it to their kids anyway... I am just doing a whole lot of thinking now because I wasn't thinking about how they would react.

Quote 2: This has been very good for me due to the fact that when I came here I was married, however, I am divorced and now remarried. I have 5 children and I feel that this will help because I don't want anyone to really decide except my children what should be done with me when these things happen. So I think this was very good for me to be here and to understand that this is what I need to do. Even though I have been married to this man now for 29 years, but my children are all grown and up there in age and I have to say, when it asked how many more years do you think you will be living, I am from a family where many of them have lived for over 100 yrs so I am 72 so I put another 25 years (laughter). So I just thank you for this opportunity for hearing these things and being able to learn some things, you never get too old to learn.

Quote 3: I was just thinking, what helped and really turned the light bulb on for me is when you gave a scenario. When you were up there

and you were saying, Ok, so when you were talking about your (mother and brother) and it was like, I know they love me but I know they are not going to make a decision. So I was able to put myself in your place and that is what made me really think about it so if there is some way that you could give some kind of a scenario or something so that they can really connect with putting yourself in that role.

Researcher shared stories, verified and clarified. The researcher shared stories from her practice and verified and clarified the discussion with participants. The stories included examples of ex-wives or estranged children showing up and being the legal decision maker; and of children having the live-in significant other removed from the hospital and not given any information. The aim was to help participants think deeper about their own situations and experiences and give some insight into the kinds of dilemmas that could arise if patient wishes are not known (See Appendix B for examples of stories). Some examples of researcher verifications and clarifications are recorded in Appendix M. One example is recorded below.

Researcher Quote: So let me summarize what I have heard so far from you and previous groups. There have been many who have said that trust was an issue both trust of the healthcare system which we primarily perceive to be white; trust of our family members and who they are; we have to face those relationships and think about who we do and don't trust, and sometimes we haven't been willing to do that in the past. And then privacy, how we have been raised to be private and that the privacy

is somehow connected with the trust because you don't want people knowing your business because you can't really trust them and that is both internally and externally, both your family and outside your family and then white people in general, just because you are black you have got to have a certain amount of protection from the world at large and then you have got to protect yourself from your local people and then you have got to protect yourself from your family. And then you throw in a little mental illness, and some drug dealing and some in prison in the mix, which we got a plenty of, and what you gonna do. So that is what I have been hearing, is that something you would agree with or can you comment on what I just said. Miss Mary.

Advisory board member comments and clarifications. An advisory board member attended most of the presentations and often added comments and clarification. Some examples of quotes from advisory board member are in Appendix N. One example of a quote is recorded below.

Advisory Board Member Quote: I know most of you people in this room. I am 69 and I am a board member and I am just taking notes just to help in terms of the research... I have 3 children and everyone is right here in Minnesota. I have written an advance directive thanks to Sandra because I realize how important it is. When you have more than one child you think that they will come to agreement but they don't necessarily. So it is just important all the way around and it keeps down so much chaos and

confusion. It helps insure your wishes and the main thing is that this is about you and you have a right to make your decisions.

What healthcare providers need to know. The researcher also asked the participants “What should healthcare providers know/do to have meaningful discussions with African-American seniors regarding advance care planning and writing advance directives?” The question was usually phrased, “If I am teaching doctors, nurses, social workers, etc., what should I teach them that will help them to have this discussion with African-American seniors?”

Quote 1: Well first of all I would go around the table just like you did originally or on my sheet here [the stimulus questionnaire, Appendix E] and find out who has or does not have advance planning and who knows what advance planning is and educate them. Explain what it is and get it going that way.

Quote 2: I think it should be in the curriculum of young doctors and I think it should be in the curriculum of high school kids, in the health classes. We should start this conversations with young people (group agreement and enthusiasm of this idea).

Quote 3: I was thinking about what you can say to the doctors. I think you should let them know that they should speak to them [African-Americans] as though they are more human and speak to them like they would any other group because we have the same intelligence, we have

everything and they would understand. But usually what happens when they come to speak to us, our group, they talk down to you in the group.

Quote 4: You can make sure that they have some sort of background where they have dealt with black people on the same level, not black people down here [pushed hand below waist]. Black people on their level and come in with that attitude. Because you can pick up that other attitude real quick. So if you are talking down to me, I am not gonna talk to you. So you need to tell them that they need to first get around some black people where they are comfortable because a lot of times, when they come in our communities, they are nervous, and that shows. So they need to be comfortable with that, but I still say that you need to look for some black people to come into some of these communities.

Quote 5: I wasn't saying that I don't want to talk to them because they are white. I want to make that real clear (me either). What I was saying is that I don't think that they are really going to connect with me.

Quote 6: ...But the reason why I didn't sign when I went to the hospital and they brought this up to me, at the time, I didn't feel like signing all of these papers and I really couldn't think about who, I kind of knew my oldest daughter would be good, be fair. So it was a lot of papers and a lot of questions and a lot of time and I said I don't, wrestling with all of this and they are all nosey, and what they gonna do with this anyway. So I think that a lot of times people just figure that it is not to any good

use. You did a very good job of explaining what it is about. I think that a lot of it, if it is explained in plain English and it is not about dying. And so keep that in there and to take time and explain it, even if they could arrange to make small house things like in the buildings where there are a lot of seniors and they have that community room, so thats a good idea.

Many participants talked about *what the patient could do* to make their relationship with the provider more meaningful.

Quote 1: I think that it is a good thing for your doctor to know a lot about your personal life too. My doctor knew that I had lost my daughter and was raising her daughter so they said they were going to do all they could to help me to be able to raise my granddaughter. Because they knew that was what I wanted.

Quote 2: First of all, if I like my doctor or whatever and I am comfortable talking to them. Like when I go to my doctor, I write all of the things that I want to talk to her about so when I go in there I have my letter that I want to talk to her about. I learned how to do that so when I go in there she knows that I have my letter and she goes right down the list and she answers everything that I have on paper. I think that she is very comfortable with me because I am comfortable with her.

Quote 3: Mine says do you have any problems or anything. Whatever is going on with me, I jot things down and whip out my notes

and they look at me like this woman means business. It is my health and I am taking charge.

Recruitment. One of the first questions asked of participants was to tell why they came to this focus group, what made them decide to participate in this research.

Quote 1: Well Liz said come to the meeting, I want you there, it is important, this is some good information we need to know. As African-American women we need to know a lot of things because a lot of times we are left out of the legal circle and then all of a sudden things are dropped down on us and we are just totally, totally lost.

Quote 2: Well Ms. I [leader of groups Wise Women and Women of Distinction] called me and told me this is what the Wise Women were doing so I wanted to get into a group to find out what seniors my age would be doing, especially women.

Quote 3: I am going to tell you, the reason I am here, really, is because Ms. I is our leader and anything that we do, she tells us and we are not hard headed. She says we are going to have this meeting, she says Wise Women want to go. She divides up and some go here. So that's why I am here, I didn't know nothing about this, it all comes from our leadership, Ms. I.

Quote 4: I came because Liz had asked me a couple of weeks ago and I told her that I had something to do today but then because she called

me again last night (laughter) I took a couple of hours off [from work] to attend this and I am glad that I did, it was interesting.

Quote 5: I am here because I don't have a directive. I have one child and she is 37 now and I am realizing that I really should, I have been inspired to get this done because she has already told me that she doesn't want to be the only one to make decisions. So we have talked about it but I want to have it on paper as to what should be done. I will get into why I guess when we have our other discussion. [associated with Wise Women]

Quote 6: At your presentation I was amazed and I wanted to find out more information so I could advance myself in my life. There has been a lot of death in my family and it seems like everybody thinks somebody else should take care of it and its really been blown out of proportion and things weren't getting done that should have been done.

Quote 7: I am going to tell you the truth, it was the money. The reason I say that was when we first heard it [about the researcher's presentation], it was in Minneapolis and I knew I wasn't going there. And when I found out we could have one here [St Paul]... I did need to redo another one because I have been to several wellness classes where they gave you they had real lawyers there to take care of that and I missed it both times...

Quote 8: ...We were told about this study through the Wise Women group with Ms. I. I thought that it would be something that I got to participate in and find out more about and also just to get to know and see what is going on out there in the community and what's happening with the seniors. The more information that I find out the better I know how to handle my life and what's best for me.

Quote 9: I heard about the meeting from Miss Sandra and I talked with her at Park Elder Center and then met her again at Oak Park and she was telling me about the program and she invited me to the meeting. I thank you for inviting me to the meeting because I learned a whole lot and I was interested in getting my will and all of that taken care of but my daughter never went to the clinic to talk to this lady about it and she told me, my baby girl told me that I have more kids than her and she feels she couldn't do it and told me to talk to my other daughters about it. So I said OK I am going to get all of you together and I am going to talk about it. So my older daughter told me, "you ain't dying yet so why should I make a decision like that."

Solutions and ideas. Many participants offered ideas about what was needed to get African-Americans to discuss and/or write advance directives and how it should be done.

Quote 1: (paraphrased) As I am listening to what everybody is saying. It seems like the way the system is, if you don't have family that

cares about you then they won't care about you. The other thing is it seems like we need to get the seniors together to discuss things. We need to get the whole family together, the young people and everything. Get the children and have them understand and they can explain to the seniors in their own language. You did a beautiful job of explaining this but if we could get the children in a group session and then have them explain it. Ask them who will speak for their parents.

Quote 2: I just thought about, how about reversing it, I am going to do this to my kids. I am going to say well do you want me to talk for you if something happens to you. Who do you want to represent you if something happens to you.

Quote 3: You know that Terri Schiavo story is very interesting [subject brought up by the participant] in that it is a great catalyst for conversation. I wouldn't want to be tubes and machines for the next 14 to 20 years, I think that certainly is a starting point for a conversation... If the amputation of a leg will save my life, do I want that or do I want to go home. It is those kinds of things that cause heartbreak when you are sick. My cousin's husband had heart problems before and he started to swell up and started hiding it from her. She was too afraid to confront him about it so they never really talked about it. When he was unable to speak and she had to make the decisions, she suffered greatly. Should I have them cut off his leg or not. She had that done [his leg amputated] and his family wasn't

happy about it and he died anyway. I think that it is imperative that we have these conversations so we at least have a starting point.

Quote 4: I think a lot of it is education. Just putting it out there and making people aware. So, how do you do that. By physically bringing somebody in and saying, listen this is what we are going to talk about and you are going to be part of it. Barring that, you have to start somewhere and you just need to do it and education is the key. (communication is needed). And communication.

Quote 5: A thought came to me, as a people vs Caucasian. I noticed that the teacher said to the children, if you had so much money what would you buy. The African-American kids said I would buy a car and the caucasian children said I would buy a home. So it all stems from what we are taught and how to look at money and how we spend money and how we preserve money and invest money. So I think the same thing applies to us as a people when it comes to how, the necessity for planning. In reference to one of the ways I think that you can go about, maybe, getting people's attention is perhaps to raise some questions in the Spokesman or Insight News [local black newspapers] like the ones in the survey (that's good, wake up time, agreement) and people see it. Then they can get to thinking this is something I should do. This is one way I think might work if you put it out there because they can't help but see it and think about it. But just to hear about it well it doesn't mean, its not as

effective as seeing these questions in the paper... Yes, because people may think that it is important to do something but what and how and these questions are self explanatory.

Quote 6: We had a family reunion and one of the things we had was a family health history. What are the illnesses in our family. That's an ideal time to talk about it when you have all of the people there and have the conversations in small groups and present it to the larger group. I think that the reason that we don't do it is because we don't think that it's anything that's under our control.

Quote 7: And it is on paper [that God-daughter is her proxy]. So I think that will solve the problem and they will just have to argue about why did you have her and we are family. "Cause I tried to talk to you and you guys wouldn't listen." I need to have this done and you wouldn't listen so this is your decision that you made. Naturally you want your family but if your family is not going to cooperate then you need to ...

Quote 8: I think what we need to do in that case [dissenting that can arise when choosing one child over another as proxy] is sit people down, the family, everybody that you want involved in that situation and put it on the table and say, XYZ and say now what are we going to do, let's deal with this and let's get a caretaker now, and let's do this. Not tomorrow but today. We need to be in control.

Others had no answers but thought it was a pressing issue and it was time to move forward.

Quote 1: I don't have any answers, no. I think a lot of our African-American background plays a part in this. Like my parents, they never talked about who was going to take care of things when they went on. They knew they had kids and we would take care of it. I think historically, the African-Americans, we have not had the pleasure of making plans and arrangements ahead of time. And I don't think that has been in our culture to do this and it goes way back and it is time now to come into the 21st century, its past time. That's part of it, that's not all of it but its part of it.

Quote 2: But that mindset is history. (that mind set is today). But we need to be aware as African-Americans. And statistics show that we are least likely to make these kinds of plans and arrangements. (and we are most likely to have high BP, diabetes and kidney failure) (laughter). Life threatening diseases than the caucasian race. (so what's going on with us, what's happening?). That's the question, and I don't have any answers.

Thanked the researcher. Many of the participants expressed their thanks for the information they obtained in the presentation and by participating in the focus group. Some said that they understood a lot of things better and would talk to their families and or write an advance directive. Most were appreciative that the researcher was African-American and said that had helped them to freely express themselves.

Quote 1: I want to thank you for coming because I am seriously now thinking of this and plan to go home and talk to my daughter and father. But something that's helping me is to have a person that looks like me, in other words an African-American, coming and sharing this information. Because there might be something that I would not have said as plainly if it was someone that I thought culturally might not understand or be aware of. So I want to say thank you and this is helping to spread the information (group enthusiastic agreement and thank yous).

Quote 2: I just want to really thank you and say how important this is. I know you know (Amen). But I just want to let you know that it is important to me that you have done this and that I am very thankful to be here because I have really been educated today (Amen) from what you have presented to us. And so I just want to say thank you. (applause)

Quote 3: Why does it always have to be somebody white teaching us. Why can't we have somebody black teaching us (lots of laughing and talking). That's why we are able to communicate with you because we are all black Americans and we all kind of been in some kind of same situations because you know and you feel comfortable.

The following chapter, Chapter 5 provides a discussion and interpretation of the data and identifies the knowledge generated from the focus group discussions.

Chapter 5: Discussion

This chapter presents reflections, discussion and interpretation of the participants' responses to the questionnaire and to the responses generated by the focus groups. The strengths and limitations of the research are discussed. Finally, a summary, conclusions, and recommendations for research and practice are offered.

Finding and Preparing Participants

The participants were black seniors living in one urban Midwestern metropolitan area who are descendants of African slaves in the United States. Traditional recruitment methods such as flyers and announcements by the researcher were essentially ineffective. Recruitment was dependent on the personal contact of trusted individuals and usually followed up with a reminder phone call a day before the event. The researcher scheduled several contacts who had agreed to participate but the researcher did not make reminder phone calls, and only two of about eight participants showed up. There was one scheduled group where no one showed up. Some of those contacts attended other groups when they were recruited by a trusted individual and received reminders. Many participants had known each other for many years, some had been friends for over 40 years, and others were related. Their relationships to each other did not seem to affect their candor; however, there were times when it appeared that the participants were glad to have the option of talking about African-Americans in general rather than their personal situations. Other times it appeared (or was stated) that their contribution was not about themselves but what they thought about African-Americans in general.

The settings were in the community and were comfortable and familiar to most participants. The participants and researchers sat at tables in board room style, except the two groups held in homes. The homes were able to accommodate the groups in comfortable living room environments. The refreshments served were much appreciated by the participants and the researcher believes that the food directly contributed to the cohesiveness of the groups. The food was served between the presentation and the focus group (when both were on the same day) and while participants were reviewing the consent. When there was a focus group only, participants were given a questionnaire and consent form to review while we waited for arrivals, and lunch was served before the focus group began. This gave the participants time to socialize and bond around the issue and the stimulus questions. Many had not been to the University of Minnesota's Urban Research and Outreach Center (UROC) in North Minneapolis (this setting was used three times). One participant commented on the fact that UROC was a place with negative connotations in that many African-Americans thought that UROC had plans to "conduct research on our children." In fact, it appears that the original plan to conduct family mental health research at the UROC site has been abandoned. This is significant because it was brought up in a discussion about ongoing distrust of the dominant culture and researchers.

Demographic and Personal Data Survey, Stimulus Questionnaire and Evaluation

Seventy percent of the participants had some education beyond high school, with 11% not completing high school. Most indicated that they had had adequate employment during their lifetime. Their medical problems were consistent with the general African-

American senior population: Hypertension 33 (63%); arthritis 28 (56%); diabetes 17 (33%); heart disease 16 (31%); and stress 15 (29%). Responses to the question about obesity were not clear, possibly because the question was poorly written. Other data from the questionnaire are addressed below.

Many participants did not want to share their age as a matter of practice. One participant listed her age as 59 but stated she was 61 in the group. There were nine participants under the age of 65 which was not expected since most of the focus groups were held during the day. Age of participants was well distributed in the groups. Some participants took time off of work to attend.

During the pilot of the survey it was noted that participants did not like the question, "How long do you believe you will live?" The question was changed to "How long do you THINK you might live?" Participants were still quite reluctant to answer the question, some stating "Only God knows" or "It's up to God." The groups were encouraged to answer the question because it was important to the research. They were told that they could use anything from their personal or family history and experience to estimate their life expectancy. Still nine (18%) participants did not complete age and years expected to live so that life expectancy could be calculated. For the 18 (40%) participants who said they would live more than 25 years, 30 years was added to their current age. Since 65% (n=28) of those responding estimated their life expectancy to be 90 years or more, it is apparent that the maximum of 30 years was not sufficient to capture higher estimates. This is interesting because most participants were aware of

health disparities of African-Americans and their shorter life expectancy; many of the participants had several life threatening diseases commonly identified.

The stimulus questionnaire proved to be very helpful in focusing the discussion of the focus groups. Many participants commented on how they had not thought about the many issues that the stimulus questions raised and thought they should be raised to the general African-American population in newspapers, public education forums, and senior living centers. Answers on the stimulus questionnaire revealed that most participants (84%) believed they would get good care in the hospital if they had insurance (question A). They were quite split about whether they would get good care if they didn't have insurance (38% agreed, 35% disagreed and 26% weren't sure or didn't answer question B). This was consistent with the discussion in the focus groups. About 70% felt like the provider had their best interest in mind (question C) but only 19% wanted their providers to make all of their decisions (question F). This was also consistent with the discussion in the focus groups.

Most participants thought that their providers encouraged them to participate in decisions about their health (81%, question D), encouraged their input (83%, question E), spends enough time with them to address their concerns (79%, question H), and explains their options in a way that they can understand them (71%, but 20% were not sure or didn't answer question I). Twenty-nine percent agreed that they did not see the same providers most of the time (question G), and 40% said they did not see their usual provider when they were in the hospital (but about 30% were not sure or didn't answer question K). Although this was not the focus of the discussion, these findings do not

seem consistent with the tone of the groups. Several participants stated that they took charge of their health by choosing their providers, even making appointments to interview them, and “firing” them if they didn’t feel like they “liked” them. Others talked about “taking charge” of their health and letting the provider know that by writing down questions and concerns and presenting the provider with this on their visit. One person wrote on the survey that her practitioner would spend more time with her if the insurance company would allow it. But the general tone of the discussions was that participants did not have respectful interactive relationships with their providers unless they demanded it. There was more of a tone of “if you take charge and let them know that you mean business, you will get the respect you deserve... if you don’t, fire them.” Participants were split on the question of whether their healthcare provider would know what they wanted if they were unable to speak, 33% agreed, 39% disagreed and 29% weren’t sure or didn’t answer question J. Only one participant said she would be comfortable with her provider making her decisions and when other participants scoffed at that, she stuck to her position. Another participant suggested that it is important to tell your provider what your personal goals are, for example, being healthy enough to take care of a grandchild after the death of a child, the group agreed.

The intended outcome of the evaluation was participant agreement with questions A, B, H, I, J and L and disagreement with questions C, D, E, F, G, K, M and N (See Table 6). Question C, “There was too much information to discuss in the short time” was the only question on the evaluation that did not meet expectations. Fifty-two percent said that they needed more time to discuss the issue and 42% said the amount of time was

adequate. This is consistent with the tone of the groups. About half of the participants seemed to want to talk more about the topic. Sometimes the participants were so engaged in thinking about what was being discussed that they were distracted from the discussion. There were 24 text comments and all were positive (Table 7). Overwhelmingly they thought that it was most helpful to have an African-American person talking to them about this issue. Most had lived in the Midwest for many years and were very acquiescent to the fact that most health professionals they encounter would not be African-American. However, they felt that they were better able to connect with an African-American on this topic. The group agreed that it is not that they “don’t want to talk to them because they are white” they just think that a white person would not connect with them as well.

The researcher also had to overcome the connection to the dominant society, in this case the University of Minnesota, and the negative connotations of research. The advisory board members who attended the focus group were most helpful in clarifying and keeping the focus on the value of the research to the community.

The main purpose of the research was to explore African-American seniors’ views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writings advance directives. The researcher and advisory board believes this purpose was met. The perspectives are detailed in the quotes of the participants which yielded the themes and recommendations.

Another purpose was to explore the use of a virtue ethics framework. The American Nurses Association (ANA) Code of Ethics (2001) is a good guide for the incorporation of virtue ethics into the role of the professional nurse. However, the ANA

Code of Ethics integrates virtue ethics from the perspective of the nurse as the expert. A *Virtue Ethics Guide to Best Practices in Community-Based participatory Research* (Schaffer, 2009) provides guidance for equality in the research process while conducting research in the community. The researcher believes community-based participatory research (CBPR) is best understood through this virtue ethics approach which is grounded in equality.

Another purpose was to gather data to use in developing a model for professionals to use to engage African-American seniors in discussing advance care planning and writing advance directives. The participants responded directly to what professionals need to know, and do, to engage with African-American seniors and made specific recommendations. These recommendations are noted in the recommendations for practice section (page 182).

Interpreting the Focus Group Themes

Initial reviews of the focus group textual transcripts revealed a number of themes related to advance care planning and writing advance directives. The reviewers identified the same statements in the transcripts as relevant and distilled similar themes. This was a surprisingly clear and consistent process. It appeared that some of the themes identified and much of the content was not directly related to advance care planning but to the history and context of the African-American experience in the United States. It was not clear how these experiences related to advance care planning and writing advance directives. However, as these experiences were repeated in group after group, the analysis team looked for meaning of these responses.

Themes were not identified for the sake of identifying themes, they were sought to give context to the “views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives among senior members of one selected urban African-American community,” which is the research question. The terms “views, feelings, attitudes...” are not defined and described. Again, the purpose is not to get bogged down in the positivist or post-positivist notions of the definitions of these terms but to use them to “stir the pot” in the hearts and minds of participants and help them to think about what their views, feelings, attitudes, etc. might be. The researcher plans to continue this project of inquiry and knowledge production regarding African-Americans and advance care planning by bringing findings and interpretations back to the actual participants and the African-American community at large. However, for the purpose of this research endeavor, the advisory board and selected knowledge production experts have contributed to the interpretation.

The researcher had planned to review the transcripts, identify themes, define and describe them denotatively and connotatively and use quotes to support the identification of the themes. This supports scientific rigor consistent with a post-positivist paradigm. However, this research was conducted in a critical theory – constructivism paradigm and is foremost a community knowledge production project. Attempts to define and describe themes objectively was counter intuitive to this approach and failed to capture what the researcher, and team of community analyzers, felt was the intent of the participants. For example: defining “fear of death” as thanatophobia, or some variation on the philosophical or religious underpinnings of death and dying, did not capture the intent of

participants in these focus groups. Fear of death for this group seemed to be associated more with the “finality” of death (which may or may not have philosophical or religious underpinnings); or the inability to conceive of the annihilation of one’s own consciousness. To get at the meaning for these participants, and to produce knowledge relevant to the research question, several quotes from the participants were used to give context to the themes, “fear of death,” “fear of talking about death,” and “death is final.” This practice was followed throughout the analysis process. For the academician the method used for identifying and defining the themes may lack objectivity and scientific rigor believed necessary to produce reliable knowledge. However, that is why the researcher committed to the virtue ethics framework, community-based participatory research approach, and critical theory – constructivism paradigms to conduct this research. This framework, approach and paradigm ensured the integrity of the research and researchers, including the advisory board, and were judged most likely to lead to knowledge that the community would value as their own and thereby lead to change.

The primary categories with themes represent those themes that would ordinarily be seen as directly related to writing an advance directive: Trust issues, fear, relationships, lack of information/knowledge and procrastination. The secondary categories with themes represent the themes that permeated the conversations when the research questions were asked: Deracination (culturally uprooted), deterioration of family/community, past discrimination, experience, self-fulfilling prophecy and religion. They are reflected upon below.

Lack of trust and fear were seen as equally contributing to the failure of African-Americans to engage in advance care planning. Lack of trust of family seemed intertwined with the deterioration of the family and often related to issues of assimilation. Participants made statements about how African-Americans didn't used to have much so there was not much to leave or worry about. Now, some of them have more "things" and they are worried about what is going to happen to their "things" so they can't trust anyone to know their business. While this sounds directly related to estate wills, it is necessary to discuss personal financial information with a person who is to be a decision maker as well. Participants didn't want family to know what they had because "they might be trying to figure out how to separate me from what little I have." Lack of trust of the healthcare system is reflected in references to Tuskegee and other discriminatory practices. Participants stated or implied that this lack of trust persists because they don't always believe that they are being listened to as an equal or respected in conversations with providers if they don't have the same level of education or income. Some expressed concern that they were being given unnecessary medicines and treatments if they had good insurance while others felt they were treated better (given more "tests and things") if they had good insurance.

Literally every group talked about death. Given the difficulties that participants expressed about talking about death and fear of death, it was interesting that they freely talked about cremation, burials, funerals, and other "after death" issues. While planning for the inevitability of death is not commonly done in African-American communities, it appeared much easier to face actual death than to think about planning for end-of-life.

Also, interestingly, religion or religious beliefs about death, dying, or an afterlife were barely mentioned. The fear of the finality of death is not a uniquely African-American concept but an in-depth discussion and analysis of this concept goes beyond the scope of this research. Redirecting the discussion back to advance care planning or “who would speak for you...” was a constant struggle. Discussions about death and funerals were allowed to continue to the extent that they helped participants recognize the value of prior planning in these kinds of difficult situations. The advisory board members in attendance were also very helpful in keeping participants focused on “who would decide for them” and away from issues related to death.

Relationships and difficulty choosing a proxy were the most salient themes for the researcher. One participant talked about how thinking about whom you have to choose among to speak for you, requires you to analyze your relationships, and this can be “damn painful.” The researcher has not found this in the literature, and it seems that this could be a major barrier to anyone completing an advance directive. This also seems consistent with many participants who talked about deterioration of family and trust issues. Other participants talked about causing family discord by choosing one family member over another. There was an intertwining of decision maker and caregiver, are they the same and what if they aren’t. Then there is burden. On the one hand, participants want to know that they have family to care for them and to make their decisions; on the other hand, they don’t want to be a burden on their children who “have their own lives and families.” While these might be concerns for all people, this might be a particular problem for African-Americans because of the difficulties they have had realizing the

“American Dream” due to injustice and racism. Again, the positives and negatives of integration come into play. African-American families have supported family members going “up north” or doing whatever it takes to make a “better life.” The thought of asking those family members to sacrifice their better life to take care of them causes extreme stress and distress.

Lack of information and knowledge is a particular problem for African-Americans as well. While information might be readily available, many African-Americans don’t avail themselves of the information because of trust, lack of sense of empowerment, fears, self-fulfilling prophecy, procrastination, or other issues. Participants talked about how African-Americans have had so many discriminatory experiences that they don’t believe/trust the information that is presented to them. Most participants did not understand the magnitude of the decisions that must be made in end-of-life situations. They were also not aware of how and why rules such as HIPAA (Health Information Portability and Accountability Act) are being enforced, and how laws about legal next of kin affect decision making in critical healthcare situations. They tended to feel that they want everything done to maintain life but most said they did not want to be “a vegetable” or be in a nursing home for years. However, they did not know where the line should be drawn of when to stop cares. They wanted to “just die in my sleep.” Also, stopping treatment amounts to giving up and giving up is not ordinarily thought of as an option either for the African-American individual or the family. While death in this country is treated with a war metaphor for the general population, to be fought with every possible resource, it is possibly more so for the African-American. This is possibly a holdover

from slavery, the fact that African-Americans are here today is because they didn't give up. It is also consistent with the fear of death and lack of trust themes. Most participants said that they needed more information and education from a trusted individual to make better informed decisions. See researcher and advisory board member clarification and verification quotes (Appendix M and N) for examples; also see examples of stories from researcher's practice (Appendix B, researcher stories) and "Thank You" quotes in findings (Page 156).

Procrastination was a category given to the failure of those with knowledge, and agreement that they should have a plan, but don't. While most participants agreed that trust, fear, relationship issues, and lack of knowledge were reasons for not engaging in advance care planning; others thought that these and other things were just excuses, and many African-Americans are just in denial. Some said that African-Americans "just don't take care of business." As one participant stated, "we have a tendency to disregard the important things. What is that old expression? We major in the minors, and minor in the majors. So that is what we have to start doing."

The secondary set of categories with themes: deracination (cultural uprooting), deterioration of family and community, past discrimination, past experience, self-fulfilling prophecy and religion. The level of responses related to slavery, Jim Crow and other historical events affecting African-Americans was a surprising finding. It was not clear how participants connected some factors such as integration or urban renewal to the decision of African-Americans to discuss or write advance care plans. However, more reflection of the analysis team revealed the connection of deracination and integration to

the loss of cultural traditions and practices which was felt to be directly related to the deterioration of the African-American family and community structure. This loss of family and community structure affects relationships and expectations of who could, should and would provide needed care and decision making. Also, who would provide care and who would make decisions was inextricably intertwined in terms of thinking and talking about relationships related to advance care planning. It goes beyond the scope of this research to analyze these findings but they are included here because of their prominence in the focus group discussions and the relationship they have to the primary categories. There is some discussion about these categories in the primary categories above.

Deterioration of the African-American family due to assimilation was a prominent theme. The orientation of society toward youth and decreased reverence for seniors was also mentioned. It appears that the seniors felt that they are not valued in the way that seniors were valued “in the old days” so they don’t know who they can trust to make decisions for them. They thought that young people should be included in this discussion, perhaps reversing the discussion and asking them who would speak for them if they were unable to speak for themselves. They talked about some seniors being “embarrassed to think that their children won’t take care of them” and others not wanting to “burden their children because they have their own life and family.” They thought that they don’t have much and the government should and will pay for them to be in a nursing home or get care they need. Seniors couldn’t conceive of there being no place for them to go or the government not taking care of them if their family doesn’t so they didn’t feel the need to

try and plan. They felt like their resources were so limited and the process seems so overwhelming that they would just let whatever happens happen.

Even when the participants had experience as a decision maker or caregiver for a family member or friend, they still didn't necessarily engage in advance planning. Most participants had experience or knowledge of dilemmas with friends or family around end-of-life issues or death and funerals but they continued to deny or procrastinate about addressing the issue for themselves. Some thought this to be a self-fulfilling prophecy; you have to affirm the positive because to speak the negative would cause it to happen. Many participants felt like most African-Americans are just consumed with "making it day to day." And then there is religion, just pray about it, the Lord will make a way.

Participants also commented on the value of the stories shared from the researcher's practice which helped them realize potential dilemmas that can arise when their wishes are not known (see Appendix B, researcher stories). They thought that education programs should be instituted through health insurance programs (like Medica, UCare), clinics (like Northpoint Health and Wellness Center in North Minneapolis), Medicare and social security, and organizations like AARP (American Association of Retired Persons). They said that hearing about potential dilemmas, learning about laws like HIPAA, and learning more about what "do everything" means might help African-American seniors to understand the importance of advance care planning.

Participants felt that providers need to have personal and social experience with African-Americans if they want to be able to connect with them professionally. They stated that when providers don't have personal or social relationships with African-

Americans, they don't know how to relate to, or connect with them. They stated that you can feel this disconnect and it breaks down communication and trust. They also thought that providers need to have this topic as part of their curriculum early on in their education. Most thought that doctors talked down to them, didn't respect them as equals. They said that information about advance care planning should be presented in the community rather than in the doctor's office or hospital so that seniors would better understand what it is and why it is important before they are sick. They also said that providers should learn how to present information about advance care planning in "plain English" and make sure they don't say that it is about dying. It is OK to say that it could be about dying but that is not necessarily what it is about, it is really about who will speak for you anytime you are too sick to speak for yourself.

Recruiting African-Americans to research or to engage in discussions about advance care planning is a formidable task for all of the reasons listed in the categories and themes. The researcher thought that because of her relationship and familiarity in the community that it would be fairly easy to get African-American seniors to participate in this research. While a cash incentive and food are important to those who agree to participate, it did not seem to attract them. It appears to this researcher that the way to recruit African-American seniors to a discussion about advance care planning is through a close, trusted individual who has vetted the researcher and the research. It is important for the participants to understand that the research will represent the community in a respectful way and the results will be useful to individuals and the community. Participants said that research is always conducted in their community but they never

know what becomes of it. Forty-eight of the 52 participants in this research signed up to receive notice of the results of the research. It is important for the participants in community-based research to feel like they are partners in the process. The participants in this research will be invited to the defense of this dissertation so they can see how the researcher presents them to the University and so they can share in the prestige of the defense of their knowledge.

Strengths and Weaknesses

There were a number of strengths to the study. The presentations were a tremendous strength. The presentations gave the participants information about advance care planning and what the research was about. The researcher made it clear that the purpose of the research was not to coerce them to write an advance directive but to find out their perspectives of why African-American seniors don't write them. The presentation included stories from the researcher's practice that introduced issues that could cause dilemmas if their wishes were not known (see Appendix B, samples of stories). The stories got the attention of potential participants and they were very complimentary of the presentations but the presentations, stories or promise of incentives did not recruit them to the study.

The stimulus questionnaire put participants on track to think about specific issues that had been identified in the literature. It reduced the need for the researcher to tell the participants what those concerns were and what we wanted to discuss.

The focus group format made it possible for the participants to share ideas and add depth to the discussion. The fact that the question was asked "What do you think

African-Americans think...” rather than “What do you think...” allowed the participants (to the extent they desired) to maintain their privacy despite the open group discussion. Another strength was the researcher’s connection to the community, both being African-American and having been seen participating in community senior activities for several years helped the participants to feel that the researcher was “connected” to them.

The advisory board members’ attendance at the focus group proved to be a strength because they were trusted by the participants. Another strength was that the research was not called end-of-life decision making because the participants did not want to talk about death or their own demise but were willing to consider who would speak for them if they were unable to speak for themselves in a critical healthcare situation.

The major weakness of the study is that it did not include random sampling. Also, many of the participants knew each other and possibly didn’t share everything they might have shared in an anonymous situation. However, this project was an effort to get a community response to a community problem. The researcher believes that the way the question was presented: “What do you think African-Americans think...?” rather than “What do you think...?” addressed this weakness and significantly canceled the negative effects. However, this non-random sample does not lend itself to predictions about African-American seniors in this or other communities.

Summary, Conclusions, and Recommendations

In this section, the work completed is reviewed and summarized. The conclusions drawn from the data are presented, and recommendations for research and practice are offered.

Summary. This research study was designed using a community-based participatory research approach to fully engage with one African-American community of seniors in this urban Midwestern community. The participants offered numerous insights into the reasons African-Americans don't engage in advance care planning and writing advance directives. Thirty themes were identified and placed in eleven categories. The categories were divided into five primary categories – those thought to be directly linked to the actual writing of an advance directive: Trust, fear of death, relationships, lack of information and knowledge, and procrastination. The remaining six categories were labeled as secondary categories – the context that participants gave to the discussion: Deracination (cultural uprooting), deterioration of family and community, past discrimination, experience, self-fulfilling prophecy and religion. There is considerable overlap in the themes and categories but the analysis team sorted them to the best of their ability. The ordering of the themes offers a sense of the order of importance or relevance that was given to a category by the participants, from the perspective of the researcher and advisory board, but this is not an ordinal or mutually exclusive list. For example, trust was a theme that was listed as a category and also a theme under other categories. The discussion of the themes is primarily from the perspective of the senior participants as they relate to their children, though they may be related to other family interactions as well.

The participants revealed that African-Americans have a cultural tradition of caring for their elders and ill family members. Despite the negative effects of slavery and racism, there was the positive effect of keeping families and communities interdependent.

This interdependence led to the expectation of seniors that they would be cared for by family and/or kinship networks if they became ill. *Therefore, there should be no need to put anything in writing.* Families also had shared values because of their interconnectedness so *there was no need to talk about values or decision making.* However, the effects of integration have provided African-Americans with more options and aspirations to assimilation into the dominant culture. Families and communities have been broken up and don't know each other like they used to, so they don't necessarily share the same values. One participant stated that so many of us "don't get to know our children as adults" because we have lived apart for so long. Participants shared that it is often difficult and even "painful" to evaluate their relationships because these relationships aren't what they used to be (don't have physical and cultural interconnectedness), or what we want them to be (committed and cohesive). But even when families were interconnected, there might be differences in opinions, and choosing one family member over another to have final authority could cause discord among family members. Participants liked talking about their "family" as a cohesive unit but when this was explored, they readily admitted that there were preferences for who they would, or would not, want to speak for them.

Participants also had concerns about talking about death and dying. For them, talking about who would speak for you if you were unable to speak was the same as talking about dying. This certainly seems reasonable since this area of planning is called end-of-life decision making by healthcare professionals. For many of them, talking about end-of-life decision making was like talking about their own death; and writing an

advance directive was like signing their own death certificate. There seemed to be an unwillingness to take some control by making their wishes known. There was a constant struggle of the researcher and advisory board member in the focus groups to keep the discussion off of “after death” issues. Participants were constantly reminded that we were talking about who would speak for you if you couldn’t speak, which is not necessarily the end-of-life.

Participants expressed that there is a general fear of death and an unwillingness to “give up the fight” to live, no matter what the circumstances, but they didn’t want to “be a vegetable.” This is not unique to African-Americans; American culture in general treats death with a “war metaphor,” to be fought with every possible resource. After a protracted illness that ends in death, one often hears at the funeral, “she (or he) fought the gallant fight” followed by a chorus of “amen.” This fear of death deters African-Americans from having discussions about advance care planning in general. But when the senior does want to talk about their wishes, perhaps the family does not. Sometimes this seemed to be because of fear but others talked about a self-fulfilling prophecy, “if you talk about it, it will happen.” Still others talked about the seniors not wanting to burden their family with this dreaded talk of death and dying, and sometimes it was the senior who would not have the discussion when the family brought it up. Some talked about when they try to talk with their children about this topic, the children make them feel like they are being “too needy;” or they become over protective and treat them like they are dying right then (don’t want them to go anywhere or do anything); or start talking about moving them to a nursing home; or tell them they don’t want to talk about it

because they (the parents) aren't dying now, or not for a long time. Sometimes when the children want to talk about making a plan, the parents won't talk. Whether this failure to communicate is due to fear, denial, trust, procrastination, lack of knowledge or some other factor is not clear. It is possible that it is due to all of these things and more. However, whatever the reason, this failure to communicate can seriously hamper making a plan for the inevitable end-of-life or who would speak for them if they are unable to speak for themselves in a critical healthcare situation.

Participants talked about their lack of trust of the dominant society, the healthcare system and even their families. While the reasons for this distrust, or mistrust, was not the focus of this research and was not explored per se, the researcher and the advisory board felt that this was an overarching theme that permeated every aspect of the discussion; and was at least an equal reason for not doing advance care planning or writing an advance directive as the fear of dying or fear of talking about death.

Past discrimination has led to a distrust of the dominant society and seemed so normal to the seniors that it was just a "given." There was no reason for anyone to explain what it was about; it was like a lens that everyone was looking through. I [deliberate use of first person] have struggled to find words to describe it here because I feel it also and it feels beyond words. It feels like trying to explain the color of grass or the sky to someone who was born blind. Members of the dominant society may see this distrust as an over-reaction, hypervigilance, or even paranoia. But there is an old adage in the African-American community that I came from about hypervigilance that can be viewed as paranoia: "Even if (or just because) you are paranoid, it doesn't mean they are

NOT out to get you.” Joy DeGruy Leary (2005) elucidates the “feelings” of this experience in her book, “Post Traumatic Slave Syndrome: America’s Legacy of Enduring Injury and Healing.” The participants all seemed to understand this syndrome and view this issue through its lens. This will be verified with the community before we move forward with publications but the advisory board members who attended the focus groups agree that this was the tone of the groups.

This level of distrust also makes it difficult to take in new information from the dominant culture. Participants in every group said that they learned information that they found useful in the presentation and focus groups and that they prefer having this information delivered by a trusted African-American. Most participants have been in the Midwest for many years and are acquiescent to that fact that they probably won’t have an African-American healthcare practitioner but they thought that they would connect better with an African-American on this topic. They also thought that the information should be presented in the community, even in their senior living complexes, and not in a hospital facility when they are ill. They also thought that the whole family, especially the “young people” should be included in the discussions. Interestingly, one participant was referring to two other participants (61 y/o) as “young people” because she has a child who was 69 years old. But others thought that young adults in their twenties, and even high school students, should be included in this discussion because there is so much death and disability associated with crime in the community. One participant suggested reversing the conversation by asking the young people “who is going to speak for you if you are

unable to speak,” to get the conversation started. Others thought that situations in the media like the Terri Schiavo case would be a good catalyst for conversation.

The participants seemed to want to give their providers credit for trying to engage them in decisions about their health (about 80% on the stimulus questionnaire) but when someone mentioned an incident or discrepancy in their health experience, the group would quickly agree with comments like “they don’t pay attention to you” or “they don’t think you know what you are talking about.” Some tried to explain this away with comments like “they would spend more time with you if the insurance company would allow them to” and others said “they are sometimes too busy to talk to you too much or nicely” but then others said that was no excuse. None of the participants in this research said that they had shared their wishes with their physician about end-of-life, even when they had completed an advance directive. It appears that these African-American seniors are anxious to learn more about advance care planning and would be willing to share their wishes with their providers if they had an education program through a trusted source and they had some assistance to work through some of their trust, fear and relationship issues.

Conclusions. Addressing advance care planning and writing advance directives with African-American seniors is a complex matter, deeply rooted in their culture and historical experience in the United States. Community education about the need for advance care planning is essential and should be done by a trusted African-American healthcare professional with experience in advance care planning. Recruiting African-American seniors to participate in these educational offerings will require connecting

with grassroots leaders and having a program vetted and accepted by them. Grassroots leaders should not be confused with large community organizations. Seniors completing the program will need assistance to identify and resolve issues preventing them from completing advance directives. African-American seniors and their families may need support to facilitate discussions with reluctant family members or help them to identify alternative decision makers.

Health professionals need to have more education and training about advance care planning in general, with special attention to working with culturally diverse populations. Health facilities and insurers, including Medicare, need to support community education and provide funding for assistance with completing advance directives prior to hospital admission.

Recommendations for Practice

Participants offered many ideas for practitioners. They suggested that there should be community education programs offered by a trusted African-American for practitioners and patients while they are in the community. They suggested that it be designed for, and presented to, all ages of African-Americans. They recommended that these presentations be done in the community, in the senior centers and senior living complexes as well as healthcare facilities. They said that healthcare plans could offer these presentations like they offer diabetes education classes, but they wanted the whole family to be involved. They also suggested that seniors should talk to their children about their wishes and ask their children who they have to speak for them. They suggested using stories in the media like the Terri Schiavo case, or some of the stories shared by the

researcher, to start conversations and point out potential problems if you don't have someone to speak for you. They suggested that healthcare professionals be educated about advance care planning, and that they should have to do one themselves. They thought that advance care planning should be in the healthcare professionals' curriculum, they should know more about them. They even suggested that it should be in the curriculum of high school children and there was much enthusiasm for this suggestion.

They recommended that providers have more social engagement with African-Americans, "so they are not afraid of us when they come into our communities." They said that providers should speak to them like they are "human" or like any other group; they should not talk down to them; they should treat them like they were equals with the same intelligence. They want them to have dealt with black people on an equal level and address them like they are on equal levels intellectually. This doesn't mean that they need to talk to them in "medical speak," there is a way to be respectful of a person's ability to understand their health situation in their own value system, without them (the patient) "being a doctor."

They also suggested things that the patient could do to make their relationship with their providers more meaningful. They suggested that patients make an effort to connect with their providers and tell them what their goals for their health are in terms of their personal life. They suggested having things that you have concerns about written down so that the doctor "knows you are in charge and you mean business." They suggested that patients find a doctor that they are comfortable with and they like because

if you don't like them you won't connect with them and that can be "dangerous" to your health.

The researcher recommends to providers. The researcher agrees with all of the recommendations of the participants. In addition to the recommendations of the participants, the researcher suggests that providers use opportunities in their practice to identify situations where they could empower patients to take charge of their advance care planning. For example, if a patient says that their blood pressure is up because they are worried about their child's drug use, he or she might ask the patient if that child is their legal next of kin and decision maker, and if they would be comfortable with that child making their decisions. They don't have to take the paternalistic role of telling the patient what they should do, but just point out the connection.

It is important that practitioners be aware of other situations with potential for ethical dilemmas such as same-sex and unmarried couples, spouse abuse, or separated but not legally divorced patients. Practitioners could also point out the fact that the patient might be the legal next of kin for their child, or other relative, who is engaged in high risk behavior (should this come up as part of the patient's health issues), they might want to consider having a plan that would decrease stress should they be called upon to make decisions for that person. In addition, practitioners could also talk to patients about identifying their personal goals for health and "their plan" for reaching those goals; this would require the patient to identify their personal values and help them enter into the realm of *probability*. Practitioners could encourage patients to make the connection of their health condition and their values to *probabilities*. This would better equip them to

decide how much they are willing to risk, for what benefit (especially when living with chronic illness), if they are to feel empowered to make decisions. Providers should also discuss and explain what “do everything” means.

The researcher recommends to the community. If community members want to take charge of their healthcare decision-making, they should identify their personal value system and think about what is important to them in terms of quality of life. They should learn what “do everything” means. Learn what respiratory and cardiac resuscitation entails in different situations and the potential side effects. Learn how and why someone becomes a “vegetable.” Think about the bottom line. “If I won’t be able to do... (What’s the bottom line?), I wouldn’t want to be kept alive artificially.” Know that this is not the same for everyone – for one person it might be, if they won’t be able to chew and eat food, for others a feeding tube might not be an issue. For some people the need for a ventilator to breathe would not be acceptable, others seem quite comfortable at the casino connected to their ventilator.

Learn about privacy laws such as HIPAA (Health Information Portability and Accountability Act) and think about who you would want to have personal information about you if you were unable to speak. Know who your legal next of kin is and if you would want that person to make healthcare decisions for you. Know if you have several family members with equal next of kin status (children, siblings, etc.) and if you think they would agree on decisions for you. Remember, if you don’t know or can’t choose, the healthcare providers can’t choose, and they all have equal say. Make sure your legal next of kin knows your current health status, your goals and values, keep them updated. If you

don't have family to make decisions for you, you should identify a friend that knows your values and goals to make decisions for you. The friend should have access to your health information. If you want someone other than your legal next of kin or you want a particular kin, to make decisions for you, it MUST be in writing, and if possible you should let your family know. You should also keep in touch with family and make sure you have their contact information in your healthcare records. If legal next of kin and/or authorized decision maker is not local, you should identify a person to have access to your health information until the authorized person can be located. If you don't have anyone to speak for you, you could write as much about your values and goals for health as possible to help the providers make the best possible decisions for you (a living will). This information should be in writing and easily accessible; at present the best way to insure this is to write an advance directive. Your advance directive should be updated or re-written whenever there are significant changes. Review it every year.

Researcher recommendations for the healthcare system. Healthcare dilemmas that arise because a patient's wishes are not known put a tremendous strain on the entire system. Patients can receive unwanted treatments and experience unnecessary suffering. Families and healthcare providers can experience undue stress and distress when patient's goals and wishes are not known, this can cause legal and moral dilemmas for providers, facilities, and insurers. This can affect the facility's reputation and their bottom line when conflicting services are not reimbursed. Even when patients want high tech care, "everything done," knowing that from the beginning supports a more efficient use of

resources. Therefore, healthcare facilities and insurers should support community education programs and the writing of advance directives prior to hospital admissions.

Recommendations for Future Research

Further research should be done to better understand how the African-American historical experience in the United States contributes to their reluctance to engage in advance care planning and writing advance directives. Further research is also needed to find out the actual social and economic value, as well as the political implications, of having an advance directive. Another area in need of research is, what resources are needed, desired, and available to people who opt out of high tech care and the implications for advance care planning.

Further research is also needed to find out the relationship of community education programs to the completion of advance directives. Completing advance directives requires assessing personal values and understanding risks and benefits of certain choices. Research should be done to evaluate how this involvement in one's own health is related to their personal goals for health and their actions to meet those goals. Research should also be done to investigate how well advance directives actually direct the provision of end-of-life care; and their effect on patients, families, and providers.

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Appendix A: PowerPoint Presentation

11/19/11

Advance Care Planning

Saundra Crump, RN, MSN, CHPN
PhD Candidate
University of Minnesota
School of Nursing

Saundra Crump is a
Minnesota Hartford
Center of Geriatric
Nursing Excellence
Scholar

This presentation is
part of the research
Ms. Crump is doing to
complete her
PhD dissertation

What is Advance Care Planning

Professionals in the health care system call this
End-of-Life Planning.

It is really planning for who would speak for
you if you were very ill and unable to speak
for yourself in a healthcare situation.

**If you are unable to
speak for yourself**

It does not mean that it is
the end of your life.

But you do need someone
to speak for you.

**How do you begin
Advance Care Planning**

1

Identify personal values

Identify Cultural and
Spiritual Strengths

Have discussions with
family and loved ones.

Ensure that your wishes
are known by family and providers.

When you will need
someone to speak for you

Is not always

Predictable

Planning is
especially important

When you have an
end-stage-disease

**What is an
End-Stage-Disease**

A progressive disease for
which there is no cure

- ❖ Diabetes
- ❖ Hypertension
- ❖ Heart Disease
- ❖ COPD (Chronic Obstructive Pulmonary Disease)
- ❖ End Stage Liver or Kidney Disease
- ❖ Cancer

Know the Law

Informed Consent

Who do you trust to consent for you?

Legal Next of Kin

Is the person you trust your legal next of kin?

Have you talked to them about what you would want?

Do you know who your legal next of kin is?

Would they agree on decisions for you?

What is HIPAA?

Health Information Portability and Accountability Act

**If you want someone
other than your legal
next of kin to speak
for you... you MUST**

Write an
Advance Directive

name a healthcare agent
(durable power of attorney)

**Why should YOU
write an
Advance
Directive?**

Health care decision making
is very complex

Individuals have the right to
make their own decisions

Making decisions during a crisis
is extremely difficult and
stressful for an individual...

and can be an impossible task
for family members

An Advance Care Plan

Tells your family and your
health care providers what
your wishes are

Saundra with Michael Schiavo and Jodi Centrozne
September, 2005



The literature shows that African-Americans are least likely to write Advance Care Plans

- What do you feel are the beliefs and values of African-American seniors about who should speak for them if they were VERY sick and unable to speak for themselves?
- What do you think affects African-American senior's views, feelings and opinions about discussing serious healthcare situations?

Key Question

What do you think is the reason African-Americans are least likely to write Advance Directives?

Focus Group

- Please join me for an approximately two-hour focus group with 4-6 seniors to discuss this issue.
- You will receive a \$25.00 gift certificate as a token of my appreciation for your participation.

THANK YOU

Appendix B: Researcher Stories

The research question has been designed so that the anecdotal stories are not directly related to the key question that is asked in the research. The data will also be aggregated so one group is not being compared to another. The key research question is “What do you think is the reason African-Americans are less likely to write their preference for care if they are very sick and unable to speak for themselves?” The anecdotal stories will be used to provide clarifying information and may be different for different groups. I will try to give this information in the presentations rather than the focus groups but will use them to clarify points. Some examples:

- Participant states that their boyfriend/girlfriend will make decisions for them. I would explain that there is a legal next of kin system mandated by law and healthcare professionals are not legally allowed to give information to other persons. Also that their legal next of kin can embrace and share with their friend but they can also totally remove their friend from the discussion. Minnesota is not a common law state.
 - An anecdotal story related to that is - A patient who lived and owned a house with a woman for more than five years was admitted with a heart attack and was on life support for 12 days. During this time his children were dutifully at his bedside and did not want him listed in the hospital directory. In fact he was listed as a “John Doe” so that if someone called and asked for him, hospital staff was required to tell them that there was no one by that name on the unit. About day 10 the girlfriend found out that he was in the hospital and just came up to the unit to see him. The children had security remove and bar her from the unit.
 - Another related anecdotal story - A patient had an affair with a woman when his children were young teenagers. He had since divorced the wife leaving her and the children to a very stressful existence and had been living with this woman for several years. When the children were in their early twenties, the man had a heart attack while attending his youngest

daughter's wedding and was in the hospital on life support. His children were his legal next of kin but the older children refused to have anything to do with him. The youngest daughter was the decision maker but his ex-wife was calling the shots and the girlfriend could say nothing.

- Yet another related anecdotal story is of a patient who had been separated from his wife for nearly 12 years but they never divorced. He had been living with a girlfriend for over 5 years. When he was brought to the hospital with a heart attack and placed on life support his "legal" wife was contacted. The wife insisted that he be sent to the VA hospital to further his care as she did not want to assume any financial responsibility for his care. The wife was told that it was unsafe to transport him but she insisted and said that she would sign release forms to relieve the hospital of responsibility if he should die. She gave the hospital 24 hours to transport him or remove her from financial responsibility. The patient was transferred. The girlfriend had nothing to say unless she was willing to accept financial responsibility for his care.
- Participant states that their grandson, nephew, etc. will make their decisions and they don't want their child who is their legal next of kin to make any decisions. I will explain that their child would ordinarily be their legal decision maker unless they had a written power of attorney. Also their child could remove the grandson/nephew from the discussion and any decision making.
 - An anecdotal story related to that is a patient whose child was released from prison because his mother was dying. When he arrived and his nephew was making decisions, he took over the decision-making even though he had not had any contact with his parent for the ten years he had been in prison.

These stories should deepen the self-reflection of participants but should not change their perceptions about why African-Americans do not write their wishes about advance care planning. I intend to make it clear that as a nurse (or other healthcare

provider) knowing a person's wishes would make it easier to provide care to them and give direction to their family (my bias). However, that is NOT the question that is being asked in this research. Participants are also not being asked to write advance directives.

Appendix C: Advance Directive Toolkit

The Minnesota Health Care Directive

A Planning Toolkit

- ◆ Why Plan Ahead
- ◆ Understand Common Terms
- ◆ Know the Facts
- ◆ Step-by-step Suggestions for Completing
- ◆ Where to Keep Copies
- ◆ A Planning Record
- ◆ Review and Update

These materials were developed by a group of professionals with expertise in law, health care, life and death health care decision making, and plain language materials development with the leadership of Marlene S. Stum, PhD, University of Minnesota Extension Service. (Updated 2008)



Why Plan Ahead?

- ◆ **Medical decision making is a patient's right.** Adults have the right to control their own medical care by consenting to or refusing medical treatment. Patients have the right to understand their health problems, potential care options, and what effect accepting or rejecting various treatments might have on their quality of life.
- ◆ **A person's right to control one's health care decisions does not end if he/she becomes incapable.** There are times when health care decisions may need to be made when an individual is no longer able to decide or communicate his/her preferences. Adults of all ages are at risk as a result of an injury or illness.
- ◆ **Putting your wishes in writing is the best way to help make sure your wishes will be known and followed by family, friends, health care providers, and others.**
- ◆ **A Health Care Directive** is a tool which allows you to:
 - Appoint another person (called an agent) to make health care decisions for you if you become unable to make or communicate decisions for yourself (Part I), or
 - Leave written instructions so that others can make decisions based on your wishes and preferences (Part II), or
 - Do both—appoint a health care agent and leave instructions.

You are encouraged, but not required, to complete both Part I and Part II of the Health Care Directive form. Knowing whom you want to make decisions for you and providing instructions to your decision-makers helps reduce future questions and conflicts.

Understand Common Terms

Advance Directive: A written tool used to guide health care decisions when an individual is unable to do so because of incapacity. Most people are familiar with the terms “living will” or “Durable Power of Attorney for Health Care” as types of advance directives.

Health Care Directive: In 1998, Minnesota law was changed to make it easier and less confusing to complete an advance directive. The new advance directive is called a “health care directive.” It combines the general purposes of the living will and durable power of attorney for health care.

Health care agent: One or more persons legally authorized to make health care decisions for another who is not able to communicate.

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Beware of Confusing a Health Care Directive with other Estate Planning Tools!

A Will: A legal document written to have control over what happens to one's property and assets when one dies. This does not involve health care decisions.

A Power of Attorney: A legal document in which one person gives another the authority to make specific financial decisions. Unless specifically written to do so, this will not cover health care decisions.

Know the Facts!

- ◆ Once a health care directive is written, it can be changed or revoked as long as you have capacity.
- ◆ It is just as important for an individual who wants to initiate or continue medical treatment to leave written instructions as it is for individuals who have other preferences.
- ◆ A health care directive does not require an attorney to complete. A suggested form and suggestions for completing are included inside to help you put your wishes in writing.
- ◆ It is illegal for a health care provider to require you to complete an advance directive. Health care providers are required to tell you about advance directive laws in Minnesota and note whether or not you have an advance directive in your medical file.
- ◆ Laws regarding advance directives are not the same in all fifty states in the U.S. If you spend a great deal of time in another state, or move to another state, be sure you understand the laws.

Step-by-Step Suggestions for Completing

Part I: Naming an Agent

Review the Agent's Duties

When naming a health care agent, select someone who is at least 18 years of age and, when possible, someone who:

- You trust;
- Has similar beliefs and values about medical care and death or dying OR is willing to carry out your wishes even if they are different from his or her own;
- Is not easily intimidated by family members, friends, or health care providers;
- Will be an advocate for your interests;

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- Can cope with making difficult life and death decisions including making decisions which would allow you to die;
- Can make decisions under stress.

Talk with Your Health Care Agent NOW!

Before naming an agent or alternate agent, talk with each person to be sure he or she is willing to:

- Serve as your health care agent
- Take time to understand and talk about your wishes
- Follow your instructions or act in your best interest

Decide if Agents Will Act Alone or Act Together

Act Alone. If you want the individuals you name to act alone when making health care decisions:

- Initial the first statement (page 1)
- Name your primary health care agent (page 2)
- You are encouraged to name at least two alternate agents to speak for you if the agent you name is unable, unwilling, or unavailable when needed (page 2)

Act Together. Individuals may want to name a spouse, adult children, or other family or friends to consult with each other and agree on what health care decisions should be made. If you want to name two or more individuals to act together:

- Initial the second statement (page 1)
- List the names using the spaces provided for primary agent and alternate agents (page 2). Attach additional pages if more than three individuals are named.

Keep in mind that a group of people may find it difficult to be available, to agree, or to understand or carry out a patient's preferences or wishes.

- If you appoint two or more persons as your health care agent, you need to say how you want decisions made, and offer suggestions on what should be done if there are disagreements. Additional instructions beyond the statement you checked on page 1 can be attached.

IF Naming a Health Care Provider...

You cannot appoint a health care provider or employee of a provider giving direct care to you when you complete this form or when decisions need to be made unless:

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- You are related to that person by blood, marriage, adoption, or registered domestic partnership OR
- You state why you want that person to serve as your health care agent (complete section on page two)

Powers of Agent

- Minnesota law allows your agent to make the same types of health care decisions that you would be able to make.
- In addition, you may want to give your agent power over some related health care decisions. Initial the line in front of each statement if you want your agent to have the power explained. Your health care agent is NOT automatically given these powers.
 - ✓ Minnesota law has changed. You are now able to have your agent make decisions for you even when you are able to make and communicate your own health care decisions. You can do this if you would prefer to have someone else make your health care decisions. If you want to do this initial the appropriate box in the “additional powers of my agent” section.
 - ✓ Minnesota law assumes that if you name your spouse or registered domestic partner as an agent you would NOT want that individual to continue as your health care agent if a dissolution, annulment, or termination of the relationship is in process or has been completed.
- You may limit the powers you want your agent to have. Use the space provided (page 3). You should carefully consider the effect of limiting your agent’s powers on his/her ability to make informed decisions regarding your care.

Part II: Leave Health Care Instructions

Why Leave Instructions?

- If you did not appoint an agent in Part I, you MUST leave some instructions in Part II for your health care directive to be valid.
- Leaving instructions helps make sure that decisions are based on your values, preferences, and wishes. While making health care decisions is never easy, knowing what a person does or does not want helps decision makers feel as if they are making the “right” decisions.

How to Leave Instructions

DO leave instructions which help others understand your health care goals, fears, concerns, and what you want as well as do not want. It is impossible to predict what specific types of health care decisions might be needed.

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You may:

- Fill in the space provided (page 3), or
- Write out your wishes on a piece of paper, or
- Use and attach the worksheet provided.

DO NOT leave instructions asking for illegal practices in Minnesota:

- Assisted suicide, mercy killing, or euthanasia
- Health care treatment that is outside of reasonable medical practice

Completing the Instructions Worksheet

The worksheet leads you through specific questions about your health care values and preferences including:

- What is most important for others to consider
 - Feelings about specific medical treatments
 - How your religious or spiritual beliefs should influence your care
 - Your beliefs about quality and length of life
 - Wishes for care when dying
 - Your preferences regarding organ and tissue donation.
- You do not have to complete all of the questions or blanks on the worksheet. Complete only those you feel will help others understand your personal wishes.
 - Do not be surprised if you find some of the questions hard to answer at first. Take time to think about and complete the worksheet. Try out your answers by talking with family and friends. Gather more information from clergy, a religious or spiritual adviser, or health care providers until you feel comfortable with your answers. Remember that there are no right or wrong answers. What is right for someone else may not be for you.

Part III: Making the Document Legal

- When completing electronically, print a copy and proof. Add all initials, signatures, and dates “by hand” on your final copy.
- You must sign and date your health care directive. A signature can be any mark you choose (such as an “X”). If you are unable to write, the document can be signed for you by someone you ask.
- Before signing: Talk with the agent and alternate agents to make sure they are willing to serve.

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- Check to make sure you have completed either Part I, Part II, or both Parts I and II.
- Have the document witnessed by a notary public or two individuals. Neither of the witnesses or the Notary Public can be named as your agent or alternate agents. Only one of the witnesses can be someone who is a direct care provider or employee of a provider on the day this form is signed.

Where to Keep Copies of Your Health Care Directive

- ✓ Give copies of your health care directive to family, friends, and health care providers so that your preferences will be known when needed. Copies (versus originals) of the form are valid. Copies should be placed:
 - ✓ In your medical record where you receive care. Ask your physician to make sure your health care directive is on file.
 - ✓ With health care providers (such as physicians, hospitals, home care, hospice). Start a discussion with your physician and share your preferences. Are your care providers willing and able to carry out your wishes?
 - ✓ With named health care agents and alternate agents. Help your decision makers understand their responsibilities and powers.
 - ✓ With family members and close friends. Inform those important to you that you have completed a health care directive, where it is, and who you have chosen as your decision makers.
- ✓ DO NOT keep your health care directive in a safe deposit box where it would not be available in an emergency.
- ✓ Indicate you have a health care directive on your Minnesota driver's license or other sources of identification in your wallet or billfold.

Health Care Directive Planning Record

Keep a master list of who has copies of your health care directive. It will be easier to make sure everyone is kept up-to-date if and when changes are made. Copies of my Health Care Directive have been given to:

_____	_____
_____	_____
_____	_____

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Review and Update Your Health Care Directive

- You can change or revoke your Health Care Directive as long as you are able to make and communicate your own health care decisions. Your most recently dated advance directive should be followed.

My most recent Health Care Directive was completed on _____
(month/day/year)

- It is not uncommon for individuals to change their opinions about who they want as agents or about specific health care instructions. Review your Health Care Directive on a regular basis, especially when there are changes in:
 - ✓ Your health status
 - ✓ Your state of residence given differences in state laws
 - ✓ The availability of individuals named as health care agent or alternate agents

Additional copies of the suggested Minnesota Health Care Directive and Planning Tool-Kit can be found at: <http://fsos.cehd.umn.edu/facultystaff/stum/healthcaredirectives.html>

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Minnesota Health Care Directive

Purpose of form

Part I. Allows you to appoint another person (called an agent) to make health care decisions if a doctor decides you are unable to do so.
 Part II. Allows you to give written instructions about what you want.
 Part III. Requires you and others to sign and date to make this legal.

My personal information

My name: _____
 Address: _____

 Home phone: () _____
 Work phone: () _____
 Date of birth: _____
 Social security #: _____

- I revoke all living wills, Durable Powers of Attorney for Health Care, or other written advance health care directives I have signed in the past.

PART 1: Naming An Agent

Agent duties

My health care agent can:

- Make health care decisions for me if I am unable to make and communicate decisions for myself.
- Make decisions based on any instructions in Part II of this document or in other documents.
- Make decisions based on what he or she knows about my wishes.
- Act in my best interests if instructions are not available.

Agent roles

- When naming my health care agent, I must choose one of the following. *Initial the line in front of the statement you WANT.*

Act alone _____ I appoint one person to serve as my primary health care agent to make decisions for me if I am unable to make or communicate these decisions for myself. My primary agent may act alone. If my primary agent is not able, willing, or available, each alternate agent I name may act alone, in the order listed.

Act together _____ I appoint two or more persons to act together as my health care agent. My primary agent and alternate agents must act together and be in agreement when making decisions. If they are not all readily available, or if they disagree, a majority of the agents who are readily available may make decisions for me.

My primary health care agent

I appoint:
Agent's name: _____
Address: _____

Home phone: () _____
Work phone: () _____

My first alternate health care agent

Agent's name: _____
Address: _____

Home phone: () _____
Work phone: () _____

My second alternate health care agent

Agent's name: _____
Address: (3 lines) _____

Home phone: () _____
Work phone: () _____

(If needed) Reasons for naming health care provider

I have named as my agent a health care provider, or employee of a health care provider, who is currently or might be providing direct care to me when decisions are needed.
____ That person is related to me by blood, marriage, registered domestic partnership, or adoption.
____ My reasons for wanting to appoint that person as my agent are:

Powers of my agent

If I am unable to decide or speak for myself, my agent has the power to:

- Consent to, refuse, or withdraw any health care, treatment, service, or procedure
- Stop or not start health care which is keeping or might keep me alive
- Choose my health care providers
- Choose where I live when I need health care and what personal security measures are needed to keep me safe.
- Obtain copies of my medical records and allow others to see them.

Additional powers of my agent

If I WANT my agent to have any of the following powers, I must initial the line in front of the statement.

I also authorize my agent to:

- Make health care decisions for me even if I am able to decide or speak for myself.
- Carry out my wishes regarding a funeral, burial, or what will happen to my body when I die.
- Make decisions about mental health treatment including electroconvulsive therapy and antipsychotic medication, including neuroleptics.
- In the event I am pregnant, determine whether to attempt to continue my pregnancy to delivery based upon my agent's understanding of my values, preferences, or instructions.
- Continue as my health care agent even if a dissolution, annulment, or termination of our marriage or domestic partnership is in process or has been completed.

Limiting the powers of my agent

I wish to limit the powers of my health care agent in the following way(s): _____

PART II: Health Care Instructions

- I give the following instructions about my health care (my values and beliefs, what I do and do not want, views about medical treatments or situations) _____

- I am attaching additional instructions concerning my health care values and preferences. *Initial one line:* _____ Yes _____ No
- I authorize donation of organs, tissue, or other body parts after my death. *Initial one line:* _____ Yes _____ No

PART III: Making This Document Legal

**My signature/
mark and
date**

I agree with everything in this document and have made this document willingly:

My signature: _____

Date: _____
(day / month / year)

Notary Public OR Witnesses

Notary Public

STATE OF MINNESOTA

NOTE: Must not be named as agent or alternate agent.

County of _____

This document was signed or acknowledged before me this _____ (day)

of _____ (month) , _____ (year) by the above named principal.

Signature of Notary Public

**Two
Witnesses**

NOTE: Only one witness can be a direct care provider or employee of a provider on the day this is signed.

This document was signed or acknowledged in my presence. I am not an agent or alternate agent in this document.

Witness Signature: _____

Address: _____

Date: _____
(month / day / year)

Witness Signature: _____

Address: _____

Date: _____
(month / day / year)

Health Care Instructions Worksheet Part II Of Minnesota Health Care Directive

MY HEALTH CARE GOALS

Having a sense of what is important to you can help your decisionmakers make health care decisions under different and complex circumstances. Read each statement below and on a scale of "0" to "4," rate how important each of the health care goals are to you. In this case, "4" means "Extremely Important" and "0" means "Not Important At All." Remember reasonable medical care should always include maintaining a person's comfort, hygiene, and human dignity.

HEALTH CARE GOALS	Not Important 0	1	Somewhat Important 2	3	Extremely Important 4
How Important Is Pain Control?					
• Being as comfortable and free from pain as possible					
• Having pain controlled, even if my ability to think clearly is reduced					
• Having pain controlled, even if it shortens my life					
How Important Is the Use of Life Prolonging Treatment When:					
• I have a reasonable chance of recovering both physically and mentally (50/50+)					
• I have some physical limitations but can socially relate to those I care about					
• I can live a longer life no matter what my physical or mental health					
• I have little or no chance of doing everyday activities I enjoy					
• I am not able to socially relate to those I care about					
• I have a terminal illness and treatment will only prolong when I die					
• I have severe and permanent brain injury and there is little chance of regaining consciousness					
• I have severe dementia or confusion and my condition will only get worse					
Importance of Finances and Health Care					
• Having my wishes followed regardless of whether or not my finances are exhausted					
• Not being a financial burden to those around me					
• Not having my health care costs affect the financial situations of those I care about					
I also want my decisionmakers to know the following things are important to me when receiving health care: _____					

My Medical Treatment Preferences

It is helpful for others to know if and why you have strong feelings about certain medical treatments. Some of the more difficult medical decisions are about treatments used to prolong life, such as those listed below. Most medical treatments can be tried for a while and then stopped if they do not help. Discuss these medical treatments with a health care professional to make sure you understand what they might mean for you given your current as well as future health conditions.

Medical Procedure	When It Is Used and Its Effects	My Feelings About This Procedure
Ventilator/Respirator A breathing machine A Do Not Intubate (DNI) order is put on your medical record when you do not want this procedure	When you cannot breathe on your own You cannot talk or eat by mouth on this machine	
Nutrition support and hydration	When you cannot eat or drink by mouth, feeding solutions can provide enough nutrition to support life indefinitely. Feeding solutions can be put through a tube in your stomach, nose, intestine, or veins.	
Cardiopulmonary Resuscitation (CPR) A Do Not Resuscitate (DNR) order is put on your medical record when you do not want this procedure.	Actions to make your heart and lungs start if they stop including pounding on your chest, electric shocks, medications, and a tube in your throat.	
Dialysis	A mechanical means of cleaning the blood when kidneys are not working.	

My feelings or concerns about other medical treatments include: _____

If I am pregnant, my feelings about medical treatment would include: _____

My Religious and Spiritual Beliefs

Religious or spiritual beliefs and traditions influence how people feel about certain medical treatments, what quality of life means to them, and how they wish to be treated when they are dying or when they have died.

My decision makers should know the following about how my religious or spiritual beliefs should affect my health care: _____

My religion/spirituality/ is: _____

My congregation/spiritual community (name, city, state): _____

I wish to have my (priest/pastor/rabbi/shaman/spiritual leader) consulted. Yes No
If yes, the person to be contacted is (name/contact information) _____

Feelings About Quality and Length of Life

I have the following beliefs about whether life should be preserved as long as possible: _____

The following kinds of mental or physical conditions would make me think that medical treatment should no longer be used to keep me alive _____

My Preferences for Care When Dying

If a choice is possible and reasonable when I am dying, I would prefer to receive care:

- At home _____
- At a hospital. Which one? _____
- At a nursing home. Which one? _____
- Through hospice services/care. Which one? _____
- From other health care providers. Which ones? _____

Other wishes I have about my care if I am dying _____

My Wishes About Donating Organs, Tissues, or Other Body Parts

Initial the lines that apply to you:

- I DO wish to donate organs, tissue, or other body parts when I die
- Any needed organs, tissue, or other body parts _____
- Only the following listed organs, tissue, or body parts _____

Limitations or special wishes I have include: _____

I DO NOT wish to donate organs, tissue, or other body parts when I die

Additional Health Care Instructions

My decision makers should also know these things about me to help them make decisions about my health care:

I agree that these are my health care instructions and have completed this willingly.

My signature: _____

Date completed: _____
(month / day / year)

• This worksheet is an attachment to my Health Care Directive:

Initial one box: Yes No

Appendix D: Biographies & Support Letters of Advisory Board

May 20, 2010

Letter of Support for the research proposal of Sandra Crump

My name is Doris Christopher and I am writing a letter of support on behalf of myself and my husband Ed for the research proposal of Sandra Crump. Her proposal, as I understand it, is aimed at trying to identify the reasons African-American seniors are so reluctant (and almost fearful) to write Advance Directives and do end-of-life planning (even when they are in a terminal situation). This lack of planning often causes stress and turmoil in the family which could have been alleviated if these tools were in place. Hopefully, the proposed research will identify some of the reasons and give health professionals information on how to approach and work more effectively with these families in this area.

I worked as a Legal Advocate for nearly 36 years and most of my clients were seniors (many African-American). I grew to love and respect seniors for their wisdom and tenacity and tried to help them solve the problems that they faced in their life situations. However, it was not unusual for one or more of my clients (at any given time) to become unable to speak for themselves (for some period of time) due to a serious injury or medical emergency. Many times they recovered, but there were a great number of times throughout my career that they did not, and the results were devastating for the families.

Even as a Black professional, I ran into reluctance and even hostility, when I tried to talk to my seniors and their families about end-of-life planning. How to successfully

approach this very delicate topic is very much needed not only for health professionals but for others such as social workers, clergy, legal advocates and others who work with seniors.

It appears to me that many people in the African-American community feel that talking about and/or planning for end-of-life situations would hasten their arrival. The fear and suspicion around this topic must be identified so that strategies can be developed to deal with them. We think that Sandra's proposal will shed some light on this very important topic and we are delighted that she has solicited our support as members of her Advisory Board. We lend our full support to her efforts and will work with her to insure that this is a successful project.

Sincerely,

Doris (& Ed) Christopher

March 28, 2010

TO WHOM THIS MAY CONCERN:

RE: Letter of support for the proposed research project: "African-American Senior's Perspectives on Advance Care Planning: A Virtue Ethics Community Based Participatory Research Approach."

This letter is written to support the above named research proposed by Sandra Crump, RN, MSN in pursuit of her dissertation for a PhD in Nursing and Bioethics from the University of Minnesota. I believe that Ms. Crump's efforts to investigate the reluctance of African-American seniors to discuss issues and make plans around end-of-life issues causes havoc in families and often spills over into the community in a negative way and cause undue stress on both groups. I feel that this research would help professionals in the health care field (as well as other helping professionals such as social workers, pastors, counselors, etc.) who work with African-American families to be aware of the cultural, religious and social issues that lead to their reluctance.

I am also concerned about the reluctance of African-Americans to participate in research that can help find answers that would benefit the African-American community. As a Black professional I am even guilty of this problem. I have always attributed my reluctance to participate in research to my anger over the Tuskegee Syphilis Study as well as other experimentation on Black Americans such as those outlined by Harriet Washington in her book, "Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present." I had the pleasure of meeting Ms. Washington at the University of Minnesota last year and this solidified my resolve. However, I now know that there are many seniors who have not even heard of many of these experiments and yet they still distrust research in general and the healthcare system in particular.

I think that religion, superstition and distrust of the healthcare system contribute to the following statements that I hear when I talk to seniors: (Religion) "I don't care what the doctor says... Doctor Jesus hasn't spoken yet and he has never lost a case." (Superstition) "Child, don't even speak about [a person] dying... he ain't dead yet... don't give air to those negative thoughts." (Distrust of healthcare system) "The

doctor told my uncle that he only had six months to live and that was ten years ago.” (Cultural) “We been the most ‘studied’ group in America and what have we gotten out of it?”

I believe that the research Ms. Crump is proposing will help to identify what is causing the hesitancy to participate in end-of-life and end-stage-disease planning and might give us some ammunition to develop some intervention strategies. I feel this would be very beneficial to the African-American individual and to the African-American community. I also believe that Ms. Crump brings mutual trust and respect to this project and will not cause any harm to the participants.

We can speculate about this matter all we want but what we need is “real data” from “real people” about what their concerns, issues, and reluctance around end-of-life discussions and planning. I applaud anyone willing to fund research in this very valuable area.

If you have any questions and/or concerns regarding this matter, or if you would like additional information, please don’t hesitate to contact me.

Sincerely,

(Mrs.) Lilene E. Moore, LISW, MSW

Elder in the African-American Community

1810 Irving Avenue North

Minneapolis, MN 55411

612-521-6581

March 31, 2010

Willie L. Daniels

Rainbow Terrace Apartments

1710 Plymouth Ave. N., Apt. 508

Minneapolis, MN 55411

TO WHOM THIS MAY CONCERN:

RE: Letter of support for the proposed research project: "African-American Senior's Perspectives on Advance Care Planning: A Virtue Ethics Community Based Participatory Research Approach."

I have been given the opportunity to read and view the proposal by Sandra Crump, RN, MSN for her dissertation for a PhD in Nursing and Bioethics at the University of Minnesota. I would like to support this research because when it comes to death and dying many older African-Americans believe that death is at God's will, but believe that life support should be continued as long as possible. A community centered approach is needed to convey serious medical information related to the end-of-life such as consents, and helping people to understand issues such as organ donation and autopsy. I believe that this is a discussion that needs to be had in the community because death is an important aspect of African-American culture with unique traditions of mourning practices, burial rites, and even the structure of cemeteries. Rather than a time of sadness, death is a time to celebrate that the deceased no longer has to endure the trials of the earthly world. Customs have been passed down from African roots in the form of expressions, superstitions, religious practices and music. At the time of death old beliefs and superstitions are remembered and may be acted upon, such as: not burying the deceased on a rainy day; or burying the deceased with feet facing east to allow rising on Judgment Day. Coins may be placed on the eyes or in the hands of the deceased, or placed around the grave site as the deceased contribution to the community of ancestors.

I believe Sandra is the person to have this discussion with this community because her professional credentials and commitment to the community will bring needed help to others in the

healthcare field. This will help to develop guidelines that might help these professionals to work with African-American families. I do not believe this discussion will cause any undue psychological trauma to the participants because they already have a set of beliefs about death and dying. This will elevate and help them by providing a framework to discuss in community, end-of-life and end-stage-disease current thinking and perhaps find other ways to view death and dying. If we begin to have this discussion with community, it will help counselors, pastors and social workers understand the reasons African-American seniors are reluctant to deal with end-of-life issues.

Overall, this will be a help to our community because it will inform African-American seniors about the care that healthcare professionals have taken to understand the cultural practices that give pause to their reluctance to deal with end-of-life talk and can feel a relief knowing that healthcare professionals CARE.

Sincerely,

Willie L. Daniels

P.S. I have worked with Sandra to develop the protocols and will continue to serve as a community advisor as she continues this process. I believe that the approach she is taking is appropriate for this type of research with this population.

Appendix E: Demographic Survey, Stimulus Questionnaire & Evaluation

_____Date

How old are you now _____ Sex: male _____ female _____

Do you identify yourself as African-American? Yes _____ No _____

How many years do you THINK you might live?

0-5__ 6-10__ 11-15__ 16-20__ 21-25__ more than 25__

Do you have healthcare insurance? Yes _____ No _____

I attended the Presentation about Advance Care Planning. Yes _____ No _____

If yes, when _____

Thinking about the healthcare provider you usually see, how much do you agree or disagree with the following statements.

1. Strongly agree
2. Agree
3. Disagree
4. Strongly disagree
5. Don't know/not sure

- A. _____ I believe that I will get good care in the hospital if I have health insurance.
- B. _____ I believe the healthcare system will serve me well if I am very sick even if I don't have health insurance.
- C. _____ I trust that my healthcare providers has my best interests in mind when making healthcare decisions about me.
- D. _____ My healthcare providers encourages me to participate in decisions about my health.
- E. _____ My healthcare providers asks for and encourages my input when planning my care.
- F. _____ I want my healthcare providers to make all of the decisions about my health and tell me what to do.
- G. _____ I do not see the same healthcare providers most of the time.

- H. _____ My healthcare providers really listen to me and spends enough time with me to address all of my concerns.
- I. _____ My healthcare providers explain all of the options of my treatment in a way that I can understand.
- J. _____ I believe that my healthcare providers would know what I want done if I was hospitalized and unable to speak for myself.
- K. _____ When I go to the hospital I don't see my usual healthcare providers.

Answer these questions Yes or No or "O" for I don't know

An advance directive is a document you sign which tells healthcare providers what your wishes are (living will) and who you would like to speak for you (durable power of attorney) if you are unable to speak for yourself.

1. _____ I have a written advance directive. **(If yes, please answer a, b & c then skip to question 7)**
- a. _____ a copy is in my medical records.
- b. _____ I discussed my wishes with my family
- c. _____ appropriate family members have a copy
2. _____ I have never heard of an advance directive, a living will or a durable power of attorney before the presentation or before today. **(If YES, go to question 7; if NO [you HAVE heard of advance directives before], please answer all remaining questions)**
3. _____ An advance directive is the same as an Estate Will or a Last Will and Testament. (What will be done with you and your things when you die.)
4. _____ Have you considered writing an advance directive?
5. _____ Have you ever had a discussion with anyone about writing an advance directive or living will?
6. _____ Having an advance directive will improve the chances that my wishes are followed if I am very sick and unable to speak for myself.
7. _____ I know who my legal next of kin is. **(If NO, skip to question 9)**
8. _____ I would be satisfied with my legal next of kin making decisions for me.
9. _____ I have been in the hospital for more than two days in the past 2 years.

10. _____ I have been to the emergency room more than once in the past two years.
11. _____ My family and friends know what I would want to have done if I was very sick and unable to speak for myself.
12. _____ I have a person to speak for me if I am unable to speak for myself and my family knows who that person is even though I don't have it written anywhere.

In the past five (5) years

13. _____ I have been so sick that my family and friends thought I was going to die.
14. _____ I have been on "life support" machines before.
15. _____ Someone close to me has been on "life support" and died.
16. _____ Someone close to me has been on "life support" and did not die.

Educational Background:

- _____ Terminal Degree (PhD, JD, MD, etc. _____)
- _____ Graduate Degree (masters, etc. _____)
- _____ 4 year college degree (what field _____)
- _____ 2 year college degree
- _____ some college but no degree
- _____ Technical/Skilled labor certification (what field _____)
- _____ completed high school
- _____ did not complete high school

What kind of work have you done most of your life? _____

Do you have any of the following medical problems

- _____ High Blood Pressure/Hypertension
- _____ Heart Disease

- _____ Diabetes
- _____ Kidney Disease
- _____ Liver Disease
- _____ Cancer – what kind _____
- _____ Lung Disease (not cancer) such as asthma, emphysema or COPD
- _____ Obesity how tall are you _____ inches how much do you weigh _____ lbs
- _____ Stress
- _____ Arthritis
- _____ Memory problems
- _____ Seizure Disorder or other brain disease
- _____ Other (please list) _____

About the Focus Group today...

Answer at the END of the Focus Group.

How much do you agree or disagree with the following statements about this focus group?

1. Strongly agree
 2. Agree
 3. Disagree
 4. Strongly disagree
 5. Don't know/not sure
- A. _____ I found the focus group discussion very interesting
 - B. _____ The focus group helped me to think more about advance care planning
 - C. _____ There was too much information to discuss in the short time
 - D. _____ The focus group leader was not clear
 - E. _____ I didn't like talking about this subject

- F. _____ The focus group leader did not allow enough time for us to talk
- G. _____ I really did not understand what the focus group was about
- H. _____ I would like more information about this subject
- I. _____ I think this is a good topic
- J. _____ I would like to see more discussions like this
- K. _____ I don't think we should talk about things like this in the community
- L. _____ I learned a lot by participating in this focus group
- M. _____ This form was too complicated to fill out
- N. _____ This subject is too personal to talk about in public

Other comments: _____

Appendix F: Recruitment Flyer

**Who would speak for you if you were
very sick and unable to speak for yourself?**



**Sandra Crump, RN, MSN
PhD candidate, University of
Minnesota**

**will present information about
Advance Care Planning
to the general population of your
facility**

To schedule a presentation

Call: 612-584-3158

Email: crum0004@umn.edu

The goals of these presentations are (1) to inform the community about Advance Care Planning and (2) to recruit African-American Seniors (60 and older) to participate in focus group research. Ms. Crump is conducting the research for her PhD dissertation.

The presentation is about one-hour long. It will explain what Advance Care Planning is and why it is important to begin thinking about who will make healthcare decisions for you if you are very sick and unable to speak for yourself.

- Participants will receive a Minnesota Health Care Directive Kit
- Presenter will answer questions about Advance Care Planning and share experiences as a critical care nurse (**NO medical or legal advice will be given**)
- Light refreshments will be served

The presentation is aimed at African-American seniors but anyone in your organization or facility is welcome to attend. Seniors are encouraged to invite their family members to attend.

Focus Groups: After the presentation African-American seniors (age 60 and older) will be invited to participate in a small-group (4-6 members) discussion that will explore group members' views, feelings, attitudes, knowledge, understanding and opinions about Advance Care Planning and writing Advance Directives. Those who take part in the approximately two-hour long group and complete a short survey **will receive a \$25.00 gift certificate** as a token of appreciation. Interested seniors may choose to participate in a focus group scheduled at a different time.

All presentations and focus groups will be conducted between August and November, 2010

Ms. Crump continually seeks and receives input from community seniors on developing and conducting this research. Feel free to contact her with any questions, comments or suggestions. **612-584-3158**, crum0004@umn.edu.

Appendix G: IRB Approval Letter

UNIVERSITY OF MINNESOTA

Twin Cities Campus

*Human Research Protection Program
Office of the Vice President for Research*

*D528 Mayo Memorial Building
420 Delaware Street S.E.
MMC 820
Minneapolis, MN 55455
Office: 612-626-5654
Fax: 612-626-6061
E-mail: irb@umn.edu or ihc@umn.edu
Website: <http://research.umn.edu/subjects/>*

July 13, 2010

Saundra K Crump
1210 11th Avenue North
Minneapolis, MN 55411-4407

RE: "African-American Senior's Perspectives on Advance Care Planning: A Virtue Ethics
Community-Based Participatory Research Approach"
IRB Code Number: **1006P84273**

Dear Dr. Crump

The referenced study was reviewed by expedited review procedures and approved on July 7, 2010. If you have applied for a grant, this date is required for certification purposes as well as the Assurance of Compliance number which is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA 00004003). Approval for the study will expire one year from that date. A report form will be sent out two months before the expiration date.

Institutional Review Board (IRB) approval of this study includes the consent form received June 16, 2010 and recruitment materials received June 16, 2010.

The IRB would like to stress that subjects who go through the consent process are considered enrolled participants and are counted toward the total number of subjects, even if they have no further participation in the study. Please keep this in mind when calculating the number of subjects you request. This study is currently approved for 100 subjects. If you desire an increase in the number of approved subjects, you will need to make a formal request to the IRB.

The code number above is assigned to your research. That number and the title of your study must be used in all communication with the IRB office.

As the Principal Investigator of this project, you are required by federal regulations to inform the IRB of any proposed changes in your research that will affect human subjects. Changes should not be initiated until written IRB approval is received. Unanticipated problems and adverse events should be reported to the IRB as they occur. Research projects are subject to continuing review and renewal. If you have any questions, call the IRB office at 612-626-5654.

On behalf of the IRB, I wish you success with your research.

We have created a short survey that will only take a couple of minutes to complete. The questions are basic, but will give us guidance on what areas are showing improvement and what areas we need to focus on:

Driven to DiscoverSM

<https://umsurvey.umn.edu/index.php?sid=36122&lang=um>

Sincerely,

Christina Dobrovolny, CIP
Research Compliance Supervisor
CD/pm
CC: Ruth Lindquist

APPROVED
07/14/10
perke001

Appendix H: Consent Form

CONSENT FORM

**African-American Senior's Perspectives
on Advance Care Planning***

You are invited to participate in a research study of African-American senior's (age 60 and above) views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives. This is sometimes called end-of-life decision-making but making decisions about who would speak for you **if you were very sick and unable to speak for yourself does not mean that it is the end of your life**. You were selected as a possible participant because you have identified as an African-American senior and have expressed a desire to participate in this focus group research after learning what it entails. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

If you prefer, you may review this form with your family and schedule to participate in a focus group at a later date. To request to participate in a later focus group you may contact the researcher. The researcher is: Saundra Crump, RN, MSN, PhD candidate in nursing and bioethics at the University of Minnesota, 612-584-3158, crum0004@umn.edu.

*A Virtue Ethics Community-Based Participatory Research Approach

Background Information:

The purpose of this study is: To explore African-American senior's (age 60 and above) views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives.

Procedures:

If you agree to be in this study, we would ask you to do the following things: **Participate in one approximately two-hour focus group** with approximately 4-6 other African-American seniors where you will **discuss your views, feelings, attitudes, knowledge, understanding, opinions and preferences for advance care planning and writing advance directives.** This focus group will be lead by Sandra Crump and **it will be audio taped** (tape recorder). Notes will be taken to **identify speakers by age and gender only.** The group meeting audio tapes will be **transcribed verbatim (typed exactly) with names removed** and replaced with secret identifiers. The researcher will identify themes and ideas from the groups. **Group data will be reported.** Participants will be able to **sign up to be notified when the results of the research are available and can receive a written summary of the findings.** There will also be **presentations of findings to the community and participants are invited to attend a presentation.**

Risks and Benefits of being in the Study:

There are **no known risks** to participating in this study.

The benefits to participation are: The researcher believes that there are some benefits to the participants because they will be given the **opportunity to think about whom will speak for you if you were to**

become very sick and unable to speak for yourself. The participants will also **learn about some of the potential problems** that can occur if they do not have a designated spokesperson or **if the person they want/expect to speak for them does not meet the privacy guidelines. NO LEGAL OF MEDICAL ADVICE WILL BE GIVEN.**

Compensation:

You will **receive a \$25.00 gift certificate** as a token of appreciation for participating in the **approximately two-hour long focus group** and completing the survey sheet. The gift certificates will be given at the completion of the focus group and participants will have to sign that they received the gift certificates. **If participants do not complete the two-hour focus group and survey, they will not receive the gift certificate.** Ms. Crump will do a presentation about what Advance Care Planning is and light refreshments will be provided, prior to consenting to participation in this research. Participants will also receive a booklet, “African-American Spiritual and Ethical Guide to End-of-Life Care” and a blank Minnesota Health Care Directive Kit if they want one.

Confidentiality:

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify an individual. Research records will be stored securely and only researchers will have access to the records.

Tape recordings of the focus group meetings will be maintained by the researcher and destroyed three (3) years after the study is completed.

Voluntary Nature of the Study:

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota or the facility where this focus group is taking place. If you decide to participate, **you are free to NOT answer any question or withdraw at any time** without affecting those relationships.

Contacts and Questions:

The researcher conducting this study is: Sandra Crump. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact the University of Minnesota, School of Nursing – Ruth Lindquist, PhD, RN, academic advisor, 612-626-5646, email: lindq002@umn.edu **OR** Sandra Crump, 612-584-3158, email: crum0004@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

You will be given a copy of this information to keep for your records.

If you wish to receive notification of the presentation of the results of this research, please fill out the contact information on the signature sheet.

Thank you,

Investigator: _____ **Date:** _____

Sandra Crump, crum0004@umn.edu, 612-584-3158

Location: _____

Statement of Consent and Signature

Page:

I have read the above information. I have asked questions and have received satisfactory answers to my questions.

I consent to participate in the study: African-American Senior's Perspectives on Advance Care Planning: A Virtue Ethics Community-Based Participatory Research Approach

Name (please print) _____

Signature: _____ Date: _____

Signature of Investigator: _____ Date: _____

I would like to receive notification of the presentation of results of this study at the following:

Name: _____

Address: _____

Phone: _____

Email: _____

Date notified _____ method _____ by _____

Appendix I: NVivo Coding Step 1

Type	Name	Memo Link	Sources	References	Created On	Created By	Modified On	Modified By
Free Node	AD – has one		1	2	7/15/2011 2:15 AM	SKC	7/15/2011 3:46 AM	SKC
Free Node	Advisory Board		5	21	7/5/2011 11:00 PM	SKC	7/15/2011 12:27 AM	SKC
Free Node	Anger over history		1	1	7/14/2011 11:26 PM	SKC	7/15/2011 3:48 AM	SKC
Free Node	Burden – being burdensome		2	4	7/12/2011 6:53 AM	SKC	7/15/2011 3:49 AM	SKC
Free Node	Caregiver v. dec. mkr		1	2	7/7/2011 3:56 PM	SKC	7/15/2011 3:55 AM	SKC
Free Node	Communication		7	34	7/6/2011 1:43 AM	SKC	7/19/2011 4:24 AM	SKC
Free Node	Community		1	7	7/5/2011 11:54 PM	SKC	7/6/2011 12:10 AM	SKC
Free Node	Culturally – deteriorated families		8	39	7/5/2011 11:52 AM	SKC	7/15/2011 2:18 AM	SKC
Free Node	Culturally don't plan		6	26	7/5/2011 2:29 PM	SKC	7/13/2011 1:02 AM	SKC
Free Node	Culturally Family Decides		7	17	7/4/2011 3:41 AM	SKC	8/8/2011 1:35 AM	SKC
Free Node	Culturally religion		4	7	7/5/2011 11:35 AM	SKC	8/8/2011 1:39 AM	SKC
Free Node	Culturally slavery		3	3	7/5/2011 11:42 AM	SKC	8/8/2011 1:39 AM	SKC
Free Node	Death is a scary thing		5	11	6/10/2011 12:10 PM	SKC	7/11/2011 1:40 PM	SKC

Type	Name	Memo Link	Sources	References	Created On	Created By	Modified On	Modified By
Free Node	Death Related		6	15	7/5/2011 10:33 PM	SKC	8/10/2011 5:49 PM	SKC
Free Node	Denial		6	12	6/24/2011 9:44 AM	SKC	7/12/2011 6:52 AM	SKC
Free Node	Dissention in family		1	2	7/14/2011 11:31 PM	SKC	7/14/2011 11:33 PM	SKC
Free Node	Don't feel empowered		4	13	7/11/2011 11:25 AM	SKC	7/14/2011 11:21 PM	SKC
Free Node	Don't Understand		2	5	7/12/2011 6:11 AM	SKC	7/15/2011 12:04 AM	SKC
Free Node	Education best from AA		1	1	7/14/2011 11:24 PM	SKC	7/15/2011 4:08 AM	SKC
Free Node	Education Needed		2	8	7/14/2011 11:23 PM	SKC	7/15/2011 2:54 AM	SKC
Free Node	Experience caregiver		4	7	7/5/2011 2:57 PM	SKC	7/15/2011 1:50 AM	SKC
Free Node	Experience decision maker		6	17	7/5/2011 2:58 PM	SKC	8/10/2011 11:03 AM	SKC
Free Node	Experience health professional		5	8	7/5/2011 3:02 PM	SKC	7/15/2011 1:49 AM	SKC
Free Node	Experience of crisis		7	13	7/6/2011 1:52 PM	SKC	8/10/2011 5:49 PM	SKC
Free Node	Experience personal illness		7	19	7/5/2011 2:58 PM	SKC	7/15/2011 2:49 AM	SKC
Free Node	Family Care		7	26	7/5/2011 11:11 PM	SKC	8/10/2011 11:03 AM	SKC
Free Node	Fear		9	20	6/24/2011 9:48 AM	SKC	8/8/2011 2:35 AM	SKC

Type	Name	Memo Link	Sources	References	Created On	Created By	Modified On	Modified By
Free Node	Final		4	7	6/24/2011 9:42 AM	SKC	7/12/2011 5:56 AM	SKC
Free Node	Government		1	9	7/5/2011 11:34 PM	SKC	7/6/2011 12:09 AM	SKC
Free Node	Hard to choose		2	5	7/12/2011 5:53 AM	SKC	8/10/2011 10:17 AM	SKC
Free Node	HC Providers need to know		9	70	7/5/2011 2:35 PM	SKC	8/29/2011 5:04 AM	SKC
Free Node	Helped me		2	3	7/11/2011 11:11 AM	SKC	7/15/2011 12:39 AM	SKC
Free Node	HIPAA		3	10	7/7/2011 7:10 PM	SKC	7/15/2011 2:20 AM	SKC
Free Node	Kinship Network		1	3	7/7/2011 6:49 PM	SKC	7/7/2011 7:29 PM	SKC
Free Node	Know your family		8	22	7/5/2011 2:18 PM	SKC	8/10/2011 11:30 AM	SKC
Free Node	Knowledge of AD-ACP		7	43	7/5/2011 2:22 PM	SKC	8/10/2011 5:49 PM	SKC
Free Node	Legal next of kin		9	32	7/5/2011 2:07 PM	SKC	8/10/2011 10:17 AM	SKC
Free Node	Money, Insurance		2	3	7/7/2011 4:11 PM	SKC	7/12/2011 6:49 AM	SKC
Free Node	Mortality		2	6	7/10/2011 1:07 PM	SKC	7/12/2011 3:35 AM	SKC
Free Node	Not about death		1	1	7/5/2011 2:07 PM	SKC	7/5/2011 2:10 PM	SKC
Free Node	Not just black people		1	1	7/5/2011 2:01 PM	SKC	7/5/2011 2:06 PM	SKC

Type	Name	Memo Link	Sources	References	Created On	Created By	Modified On	Modified By
Free Node	Overprotective		1	1	7/13/2011 12:50 AM	SKC	7/13/2011 12:50 AM	SKC
Free Node	Plan to write now		3	4	7/7/2011 8:04 PM	SKC	7/13/2011 1:56 AM	SKC
Free Node	Planning – gift to family		3	10	7/5/2011 10:52 PM	SKC	7/7/2011 5:27 PM	SKC
Free Node	Privacy & secrecy		5	23	7/6/2011 2:30 AM	SKC	7/15/2011 2:35 AM	SKC
Free Node	Proactive		1	2	7/13/2011 1:48 AM	SKC	7/14/2011 11:11 PM	SKC
Free Node	Procrastination		7	26	7/5/2011 11:22 PM	SKC	8/10/2011 5:49 PM	SKC
Free Node	Quality of life		3	7	7/5/2011 2:13 PM	SKC	7/15/2011 12:37 AM	SKC
Free Node	Questioning or Clarifying		8	54	7/5/2011 10:59 PM	SKC	7/15/2011 2:12 AM	SKC
Free Node	Quote		6	28	7/5/2011 10:48 PM	SKC	7/15/2011 4:16 AM	SKC
Free Node	Recruitment		7	31	7/5/2011 3:05 PM	SKC	8/10/2011 5:49 PM	SKC
Free Node	Reduces stress and discord		5	8	7/5/2011 11:08 PM	SKC	7/12/2011 8:23 AM	SKC
Free Node	Relationship with provider		6	15	7/5/2011 2:45 PM	SKC	7/15/2011 2:41 AM	SKC
Free Node	Relationships family-friends		3	14	7/7/2011 12:26 PM	SKC	8/10/2011 10:17 AM	SKC
Free Node	Religion – Spirituality		7	13	7/5/2011 11:43 PM	SKC	7/15/2011 2:45 AM	SKC

Type	Name	Memo Link	Sources	References	Created On	Created By	Modified On	Modified By
Free Node	Schiavo		2	2	7/15/2011 2:13 AM	SKC	7/15/2011 4:19 AM	SKC
Free Node	Superstition		7	11	7/5/2011 1:56 PM	SKC	8/8/2011 2:35 AM	SKC
Free Node	Thanks for info		3	9	7/11/2011 11:05 AM	SKC	7/13/2011 2:00 AM	SKC
Free Node	Trust – Lack of trust		7	38	7/6/2011 2:22 AM	SKC	8/29/2011 5:04 AM	SKC
Free Node	Tuskegee		0	0	7/15/2011 4:20 AM	SKC	7/15/2011 4:20 AM	SKC
Free Node	Values		4	8	7/7/2011 4:13 PM	SKC	7/12/2011 6:46 AM	SKC
Free Node	Wise Women		1	2	7/12/2011 3:42 AM	SKC	7/12/2011 3:48 AM	SKC
Free Node	Won't write		5	12	6/24/2011 10:05 AM	SKC	7/12/2011 5:56 AM	SKC
Free Node	Young People		4	10	7/7/2011 7:28 PM	SKC	7/15/2011 12:54 AM	SKC

Appendix J: CWC Coding Step 2

Notes received from Cultural Wellness Center re: Knowledge Production,

Received 8/10/11

9/20

- Fear of death – denial, so final
- Have relied on central figure – matriarch or patriarch, families have deteriorated, no one in authority
- Hard to choose who in family has final say
- Slavery – massa made the decisions
- Don't have spirituality any more to help make decisions
- Hard to put something down on paper -- Don't know why so hard
- Who will do research to make good decision, might have to trust doctor
- Problems of not having directive – any child can decide
- Not talking about death decision but about life decision – changes perspective
- AAs don't value quality of life, but I do – don't want to be hooked up to tubes
- Suspect keep people alive for the insurance, or just wanna kill black folks
- Sometimes children change your decision when you can no longer speak
- You should talk to family members about this
- Verbal not good enough
- Why AAs less likely to have advance directives? Family lives far from each other
- We major in the minors and minor in the majors – we have to make the effort to talk about this
- Knowledge is power
- Young people don't want to deal with this
- This is going to have to be done because people are living longer
- It's a good thing – addresses ethics
- Have to get to know healthcare provider to have this conversation
- Problem getting people to talk about it

9/29

- I was a caregiver for mother with Alzheimer's, and so want to know about available resources
- Here because friend referred me
- I was in a coma and want to make things easy for my children
- My husband told me his wishes before he died and that made it much easier
- Cremation or old school
- Parents owe it to their kids

- Write it down so no question
- Why do some do and some don't?
 - If you have gone through a death and they didn't have insurance, if things go wrong
 - Don't feel anything is going to happen
 - Feel we've got time,
 - Live day by day
 - The more educated we are, the more responsible
 - Used to see death, now kids not conscious of it
 - Carryover from slavery – the NOW syndrome – can't count on a future
 - We used to look up to our seniors – now we look down to our youth
 - We had fathers in the house
 - Disconnection/disrespect between generations
 - Church was important
 - Youth don't understand death because parents not sitting down to talk to them
 - Don't have community
 - Integration helped and hurt – now we can move around, far from each other; before busing teachers knew all the kids in a family
- A lot of us embarrassed to think our kids won't take care of us – because the women have to work
- Welfare mentality – the gov't should take care of you
- People don't want to think that there might be no one to take care of them
- A lot of people in my building don't like participating in things – take food to their room
- What teach white people to talk to black people about this?
 - They should have experience talking to black people, not down to them, not nervous
 - Should get money to pay black people to go into the community and have discussions about this

10/03

- We're afraid to die
- We don't trust like we should
- Don't want anyone outside the family to know our business
- Don't want to just talk about death, but who will make decisions if you can't
- This discussion is needed for the future
- Need to write it down because only son can't deal with it, and a strong relative would take over

- Need directive so don't disagree with parent and feel guilty about doing something she would disagree with.
- Gives you peace of mind
- Family reunion good place to have this conversation
- I heard your presentation and now I want to put my wishes in writing
- Painful that family doesn't give a hoot about me – this makes me think about that
- Woman angry that hospital made her fill out a living will – felt it invaded her privacy. Had 11 siblings and no one would come to be with her in hospital
- People feel it's nobody's business and doesn't need to be written anywhere
- Feel like you're signing your death certificate when you write it down
- Who give copies to?
- Have to find legal next of kin (HIPPA)
- Someone who will sit by the bedside with you might not be the same person who can make decisions for you
- What makes life worth living? Different people will have different answers
- Blacks don't want to go out in public with trachs and bags – vain, privacy issues
- Some people don't want visitors in the hospital because of how they look
- Writing an AD is like signing your death warrant
- Not about end of life but who will speak for you
- Health care professionals separate this – not talk down to people
- Don't trust surgeons, health professionals
- Trust issues go back to Tuskegee
- Questions about daughter's role with doctor when mom can speak for herself

10/3 Glendale

- Important because AAs often left out of the legal circle
- I'm here because we should live like we could die tomorrow
- Important because we AAs often feel our privacy is being invaded
- Writing an AD is like signing your death warrant
- We have a concept of death that it is fearful
- Have seen what happens when people don't prepare
- Superstition that if you talk about it, it will happen
- Problem of close friends not being able to get info or make decisions without it in writing
- Parents shielded us from things
- People think you're going to heaven, so why worry about it?
- But it doesn't mean you're going to die, if can't speak for yourself
- We don't want to think about who's not reliable
- Restrictions of HIPAA
- Secrecy is a problem – not wanting people to know your business

- Discussion forces you to think about relationships, maybe mend them, also think about what need to do to live longer
- This is a major cause of moral distress for nurses – family’s arguing
- How resuscitation can break ribs, cause pain

10/7

- The older I get, the more I think about it
- Maybe this will inspire me to take next step
- How is a lay person suppose to know at what point you don’t want to live anymore?
- No matter what I put down there it will be up to [my daughters]
- I know this is about the medical end but it all kind of fits together for the future
- My daughter:”you ain’t dying yet, so why should I make a decision like that?”
- All I can see is my two daughters arguing over who is going to do what. I just say it’s time for me to make a decision
- This makes me deal with my own mortality. I really didn’t want to face it until my sister had a stroke
- You keep thinking you have a lot of time. I lost my son last October...it gave me a sense of my own mortality
- The only time I get serious about what I should do is when I am going to take a flight
- Difference between young and old is wanting to talk about this – Have you thought of mixing the two groups?
- What helped and really turned on the light bulb on for me Is when you gave a scenario.
- Importance of knowing your legal next of kin can make decisions for you – can put out whoever they want. You can name someone not next of kin, must be in writing
- A lot of people just don’t want to be involved nothing
- A lot of AAs have been hurt and they done so many failures so they are just trying to make it. They don’t want to get involved in stuff. – they are just trying to make it and live day by day
- Wondering if it is a holdover from the old days – It is sort of like if you start preparing for something it is going to happen. Wonder if it’s a cultural thing. Two Caucasian people I know have taken care of it.
- Whatever money I have I am going to try to spend it on me now.
- Teacher asked what would you buy if you had so much money?: The AA kids said I would buy a car and the Caucasian a home. It all stems from what we are taught and how to look at money. Same thing with planning.
- Get people’s attention with questions in the AA newspapers.
- People think their doctor is going to do it or they think if they have ins it will be OK.
- It’s a good idea to have this discussion.
- But I have all these things I have to do but I can’t cope with this right now.

- Thought ACP was about paying for your funeral. But all it is is making sure the doctor knows.
- We are not taught when we are coming up. These things have to be taught early and when they are not there is fear in us – it is lack of education
- You get complacent
- Yes, it's postponement – I will do it tomorrow.
- It has to do with fear.
- It would be less threatening at 60 on down to say if I am brain dead, I don't want to be revived
- Summary: fear, superstition, too busy – just surviving, procrastinating
- We are not taught these things. Our lack of understanding keeps us from growing.
- Questions you raise should be in the media
- We've got a fear in us – it's about culture and a little about we have been denied so much as far as AAs. It's fear that we are going
- Fear of rejection or someone not going to pay you no attention or not believe you
- What would a white professional have to do to get you to have this conversation?
 - I don't know that you know, can empathize with me. You have my interest at heart but there is still that little piece that I am kind of hesitant to really open up
 - Why does it always have to be someone white teaching us?
 - I don't think they're really going to connect with me
- Maybe what's wrong with us is that we gonna pray – maybe that's part of the problem

10/18

- Knowing my children it's going to be a lot of squabbles, so I pre-paid my funeral and put together my whole service. My ex-husband's didn't even have children and his children still [dealing with it]
- I kinda whisper to my daughters to tell them little stuff to do but not down to details because I guess I don't think I am going to die but I know I am
- I don't know which one I would tell to do what because they wouldn't agree on nothing
- There is a fear factor, but after you have done it, it releases some of that
- It seems to me that it takes a word of mouth
- The reason I am here is because Ms. Irwin is our leader
- A lot of black people don't understand a lot of stuff because it was taken from us. And then when it did come out we have a hard time viewing it. They are afraid you are trying to take them for something or they are afraid you are trying to get over with something.
- Hard for black people to trust each other

- They would rather hear it from a white person
- Hard for us to trust our own family members
- We don't talk to each other, don't tell people your business. Told you don't need to ask – it's passed on to the generations.
- We need to start with the young people and tell them so they know how to plan this kind of stuff
- We don't know what people died of
- White people feel like if it is not in their hand they don't have control – that is one of the reasons that they don't tell everybody their business
- We have been taught to distrust white folks and all that, but our own family, that's unfortunate
- White people will take it all away, so you have to keep it close to the chest
- Prior to integration we knew each other's business but we could still depend on each other
- Seniors, AAs or blacks are being pushed to be, to fend for themselves
- Family is too busy to help them and they have to make the decision on their own – my family don't care and they don't need to know so I am going to keep this all within myself
- I would depend on the person taking care of me
- Summary: trust, privacy protection from the world
- “Oh, mama, don't talk about that”
- Really hard to make a decision
- People can have input into the decision, but not the burden of making it
- It's a burden we're putting on people not to designate someone
- AAs are very reluctant to put things on paper
- If they say something it's going to come true
- We need to know the values around health
- It could be a miracle
- Communication is number 1

Major Themes:

Trust:

- Of family members: Families have deteriorated, disconnection, disrespect
- Of doctors: want to keep you alive for insurance? Tuskegee
- Hard to have trusting and long-standing relationship with a doctor
- Mistrust of putting things in writing
- If you sign something, doctors may not do as much as they could for you.
- Don't want people to know our business/privacy

Education:

- We need to understand more why this is necessary
- Scenarios helpful
- Importance of understanding the law
- Articles in black newspapers would be helpful

Problem with talking about it:

- Fear of death
- Superstition: If you talk about it, it will come true
- People don't want to face difficult relationships, that someone might not be reliable
- Have to face there might not be someone you trust enough
- People living day to day hard enough
- Death is more hidden from us
- Generational differences: young people don't see the need, don't want to talk about it
- Gender differences: Men don't want to talk about it, avoid going to doctor
- Brings up difficulty of understanding what quality of life means to you, particularly what a life sustained by technology means or looks like.
- Sometimes, having bad experience motivates people to do it for themselves
- Procrastination
- We expect a miracle
- At hospital or clinic, importance of advanced directive not emphasized – doctors and nurses are not persuasive; communication has limitations – not enough time, don't listen well or make a connection

Difficulty of choosing a person:

- Because of impact on other relationships
- Judging who's best at making decisions, not who closest too
- Confusion about what qualifies a person to be a good decision maker
- Don't want to burden people

Effect of historical trauma:

- Slavery – others made decisions for you
- Integration helped and hurt, families now more dispersed and disconnected, communities disbanded, support systems are lacking
- Government should take care of you
- A lot has been taken from us, and when we do learn, we have mistrust

- Learned from white people not to tell people your business
- White people will take it away if you share it
- People used to fending for themselves

How teach white people to talk to black people about this?

- Should have experience with black people, not be nervous
- Should not talk down to black people, but establish a connection
- Black people should be paid to talk to black people
- Black people will not open up to white people like they will for black people
- One strategy would be to offer classes for seniors that combine advance directives with writing a will.

Appendix K: Collapsed Themes Step 3

Step 3 - Collapsed themes identified by researcher and Cultural Wellness Center knowledge production staff

1. Loss of culture and community
2. Slavery
3. Integration
4. Feeling that the government owes them
5. Deterioration of the family
6. Assimilation into the dominant culture
7. Fear of death
8. Fear of talking about death
9. Death is so final
10. Signing advance directive feels like signing own death certificate
11. Denial
12. Procrastination
13. Excuses
14. Burdensome for person affected or family member to talk about advance care planning
15. Religion
16. Positive affirmation
17. Not speaking the negative into existence
18. Past discrimination
19. Lack of sense of empowerment
20. Lack of information and knowledge
21. Lack of resources (income, insurance, education, family & community support)
22. Lack of trust
23. Relationships (choosing among family members is difficult)
24. Privacy & secrecy
25. Society becoming more youth oriented
26. Lack of reverence for elders
27. Experience as caregivers and/or decision maker for family or friend
28. HIPAA (Health Information Portability and Accountability Act)
29. Experience with death and funerals
30. Already have an advance directive

Appendix L: Advisory Board Meeting Notes Step 4

Advisory Board Meeting 8-18-11

Deracination

- Slavery
- Integration
- Loss of culture/community

- Death/funerals
-

Deterioration of family/community

- Assimilation
- Burdensome
- Society is youth oriented
- Decreased reverence for seniors
- Difficulty choosing among family members

- Denial
 - Procrastination
 - Excuses
-

Past Discrimination

- Lack of sense of empowerment
- Trust issues
- Government owes them
- Lack of information/knowledge
- Lack of resources

- HIPAA
-

Fear

- Of death
- Of talking about death
- Signing is like signing death certificate
- Death is final

- Already have AD
-

Superstition???

- Positive affirmations
- Don't speak negative into existence

- Privacy & Secrecy

Experience

- Caregiver/decision maker

Attended: Doris & Ed Christopher, Liz Moore, Willie Daniels

Meeting was from 1-5pm, lunch was served.

Liz had reviewed the themes and come up with categories to organize them. She did not know that was what needed to be done.

Deracination, etc. Much discussion about what slavery, integration, past discrimination, etc. had to do with writing ADs. Explained that this came up in most groups in response to the question and could not be ignored. Explained that I had re-listened to the tapes and although sometimes it seemed off topic, it still kept coming up in response to question so I had to analyze it. I will need to run it past the participants to see if they think I handled this appropriately.

Religion: Liz thought that there should have been a category about religion. I explained that while I thought that there would be more discussion about religion it just wasn't there. There were a couple of people who said "all I have is Jesus" and "I have a disease and I expect God to heal me" and one person said she was "ready to die when her time comes." I didn't think there were enough references for a category but I plan to address religion (with quotes) in the discussion. I will re-look at this though.

Trust: Doris thought that the primary theme was Trust, that should be #1. She also thought that ACP should be part of the practitioner's curriculum. She talked about how Poverty Law didn't come into mainstream until someone wrote a dissertation on it years ago.

Fear: Liz thought that fear was a key theme.

Superstition: We talked about another name for the category "superstition" and Liz had already listed it as "self-fulfilling prophecy" and I think that works.

Relationships: This was the key theme for Sandra. The notion that people don't want to think about advance care planning or who would speak for them because it forces them to evaluate their family and personal relationships and see them for what they really are. This was not found in the literature so it appears to be a new finding.

Categories agreed upon by researcher and advisory board

Primary Categories

1. Trust Issues
 - Family
 - Healthcare providers
 - HC system in general

2. Fear
 - Of death
 - Of talking about death
 - Signing is like signing death certificate
 - Death is final

3. Relationships
 - Burdensome
 - Difficulty choosing among family members
 - Trust issues
 - Communication issues

4. Lack of information/knowledge
 - HIPAA
 - Trust issues

5. Procrastination
 - Denial
 - Excuses

Secondary Categories

1. Deracination
 - Slavery
 - Integration
 - Loss of culture/community

2. Deterioration of family/community
 - Assimilation
 - Society is youth oriented
 - Decreased reverence for seniors
3. Past Discrimination
 - Lack of sense of empowerment
 - Government owes them
 - Lack of resources
4. Experience
 - Caregiver/decision maker
 - Death/funeral
5. Self-fulfilling Prophecy
 - Affirm the positive
 - Don't speak the negative into existence
6. Religion
 - ...

Agenda
Advisory Board Meeting
August 18, 2011

- Review what you think about themes identified
- Review what you think about quotes (too many, relevance, etc.)
- Discussion: What does this all mean?
- Are these findings in keeping with the intent of research AND respecting community

Recruitment

- By trusted person
- Personal contact
- Reminder phone call
- Only one person said money

What healthcare providers need to know

- Find out if doctors have one and if THEY know what they are
- Put it in their curriculum
- They should speak to AAs like they are equals
- They should have experience with AAs on an equal level (be comfortable with blacks)
- It would be better to have black people to connect with on this subject
- They need to give clear explanations (in plain English) of why ADs are needed

- They need to know as much as possible about the patient as a person

What patients can do to improve relationships with HC providers

- Tell them about your personal life (goals & expectations for health and quality of life)
- Like your doctor (if you don't, get another one)
- Write down what you want to talk about before you get there
- Let them know you are serious about your health, you are in charge & mean business

Doesn't work

- Flyers
- Announcements
- Calling it end-of-life

Already have an AD

- Done with will

About participation in focus
groups

- Stimulus questions were very helpful
- Participants input and perspective was respected

Appendix M: Researcher Verification Quotes

Researcher quotes to clarify and verify information in focus groups.

Researcher Quote 1: How many of you know about advance care planning, what have you heard about advance directives, living wills, end of life decision making? So one of the things I want to know is what is your knowledge about them, what do you think that black people know? I actually wrote my questions in a particular way. So let me just share that with you too. I wrote the question to say what are your perceptions of what African-Americans think. So when you tell me about something, about why you think people do or don't do something, it can be from your own personal experience or not. You don't have to feel like you are telling your own business. You can just say sometimes don't do, or sometimes children are in jail. You don't have to talk about whatever if you don't want to. I deliberately made the question about what do you think African-Americans think about it. Why do you think they don't write advance directives?

Researcher Quote 2: Yes I am saying this [advance directive kit] tells you what to do with them. Who to give it to. You need to redo it when something new happens or your medical diagnosis or life changes. You send them to everybody, you keep one, you give them to all your family members that are important to the discussion so that they know. The first thing you do is have a conversation around the kitchen table where you

say, this is what I wrote and this is why. I said I don't want a feeding tube because if I am never going to be able to eat again in my life I don't want to be fed with no tube, period. So if somebody says, "but mama that's just a little bitty little thing, it only takes 20 min, its not that invasive." [you can say] "I don't care, if I can't make the decision, I am telling you now that if I am never going to be able to swallow food again in my life, don't artificially prolong my life." Now I ain't saying nobody needs to kill me, I ain't looking to be killed or to die. I am saying, if I am to that place and I get a chance to get out of here with something sudden, don't try to get me back if I am already to that place. So that's the other thing too. We act like that to not prolong somebody's life is to cause their death. You hear all of the time, if God wants me God will take me. Well, I have a friend whose mom has Alzheimers, does not recognize him, he keeps her at home, he is an incredible son. He was between 50 and 65 at that time and he had her at home. He had people come to stay with her during the day and he had a whole schedule that he paid for out of his pocket. He said sometimes she could talk a little but didn't know who he was. She had had a couple of heart attacks and pneumonia... he was giving IV antibiotics at home... So I was trying to gently talk to him... Well, B what do you think, I mean is there some point where you might... [he said] "When the good Lord gets ready for her he will take her." [I said] "Well B, sounds like the good Lord has been there to get her a few times." (laughter). And I have done due

battle with the good Lord, let me tell you. Cause if you ain't gone by the first half of my shift in the ICU, I got enough drugs, you ain't going no where. Really, it is hard to die in an ICU. A decision has to be made to stop doing something for you to die in an ICU about 90% of the time because we have got something that we can tweak... People don't realize how hard it is to die once you get in there and get on the machines and drugs. I have had people on as many as 15 IV pumps getting 20 or 30 antibiotics in a 24 hour period. Suctioning them every few minutes, raisisng them up off of the bed suctioning. Ribs broken from resuscitation, still resuscitating them. People don't know what "do everything" means. So you get to learn what do everything means. People don't realize that you have a good chance of your ribs being broken anytime you are resuscitated but by the time you are 70ish, 99% of the time your ribs are going to be broken when you get resuscitated (surprised expressions). You can't have nobody leaning into your chest like that without breaking your ribs. A fair amount of times they puncture your lungs or they cause some other kind of pains. All of this, if you have got osteoporosis, arthritis... people don't know what all of that means. You don't need to know all of that but if you just think about all of that and say, what does it mean to be in pain for you. Some people say, now I can tolerate a lot of pain, don't be pulling no plug just cause I am in a little pain. Some people are like, I have zero tolerance for pain. If I have got something that I am going to be

in pain for some long period of time, that is kind of my decision maker. So different people have different ideas about those things. Some people are just vain, don't want to look bad. If I am going to deteriorate from this disease and lose 75% of my weight... and I am going to be in pain too, don't try to resuscitate me. We are not saying do nothing to cause you to die, we are saying don't do nothing to bring you back... let natural death occur. That is a different thing. We don't have a concept of that.

Researcher Quote 3: I think what is important about what you just said [plan for funeral] is how much peace was brought about having that discussion up front. Back to what we are talking about is making that decision in the hospital. In the same way there is not all of that confusion, the same things happens when you have discussions about end-of-life, about what you value, about what's important to you. We may not know what we should do but most of us have experienced somebody being sick in the hospital and seeing the family going through a mess. Sometimes we don't talk about it because you know you don't be talking about folk's business (that's true). You are like Lord, did you see how they acted (laughter). Yet we don't go home and try to keep our people from acting like this. So, we do know, that's what I am trying to find out. We claim we don't know but we do know. And even if you didn't write anything, when you went to the hospital and saw Susie, Sallie, my friend or whatever kids clowning; or when you know somebody's children out there on drugs,

*doing whatever, they get sick and ask who their next of kin is and they go--
-, y'all see all of that. How come we don't do it. That's what I want you to
tell me. What is it that makes us see that and not do it. Can you tell me,
Miss G.*

*Researcher Quote 4: Let me do a summary of what I think I heard.
The truth of the matter is you guys have tap danced around this subject
(laughing). You said I think there is some fear but I didn't get what causes
the fear. Why I fear. That maybe there is some superstition, kind of like if
we say its going to happen then it will. Like playing the numbers, if you
dream it its going to happen (laughter). We don't have time. We are too
busy worrying about day to day, just surviving, life itself is so
overwhelming and we don't want to think about anything other than
surviving. The other thing on that was we are just busy doing other things
and procrastinating, we kind of get it but think its not that important. Did I
miss something?*

*Researcher Quote 5: Like people say they are not going to make
any decisions because God is going to take care of it. And I say, I don't
doubt that. Maybe God is going to talk to your people but God don't be
talking to me. So which one of your people do you want to talk to me?*

*Researcher Quote 6: ...OK, these are facts: when you are down for
longer than 6 minutes without air, you more than likely are going to have
brain damage (group agreement). You are out at Old Country*

[Buffet](OCB) after church one Sunday with all your family, you go to the bathroom and on the way back you fall down and have a heart attack, stroke, whatever. They call 911 and by the time they get there and get going on you it has been about 6 or 7 minutes, 5 minutes, 6 minutes. You are 80. Now you can play with 80 cause I ain't mad at you, you are looking cute at 80, I ain't mad at that. But the fact is, if you have been down on the ground without oxygen to your brain for 6 minutes at 80 years old, do you want us to try to save you? Or do you want to leave this world with a nice quick heart attack out at OCB after church?

Researcher Quote 7: No, see that's what I am telling folks who say they going to pray. So what I am saying is, the better shape you are in, the more important it is to talk to your family about whats important to you about being in the shape you're in, about making decisions as things happen. Because, what I have found, what it seems to me is, that people who are very healthy and independent are not very interested in being unhealthy and in nursing homes even if they can get a couple of more years. So that's more important than the person who has got something wrong and been sick for a long time, they might be able to tolerate OK, whatever. But, its not like when my time comes I just go, it don't work like that. Cause we say when my time comes I just go but when you talking to the person's family and say they have been down for 15 minutes, they are

not going to have much brain function. "Well you don't know that, it could be a miracle." (group: that's right)

Appendix N: Advisory Board Comments

Advisory Board member comments and clarification quotes.

Advisory Board Member Quote 1: Well it is more typical in the black experience that we are more likely to talk about it but not very likely to put it down on paper. Why can't we put it down on paper, even when we identify in our mind, I know Judy is going to take care of me. But I am saying, why can't we put it down on paper if we really want that to happen. If it is going to happen, you need an advance directive. If you have a number of children. But sometimes we verbalize that but we still don't want to sit down and write one of these, why not?

Advisory Board Member Quote 2: We keep talking about death; we are not talking about death. Especially here, you can go out here in Minnesota and in this ice... and fall down and hit your head and get a concussion for a day or two weeks, or a lot of seniors have problems falling in the bath tub, we are talking about who would speak for you while you are alive. It might lead to death but most of the time, like Sandra said, most of the people who come into ICU are not able to speak for themselves but most of them come out, 90%. So its during that period when you can't speak for yourself where medical decisions have to be made... same day surgery example, they go out and ask the next of kin... So its who will speak for you.

Advisory Board Member Quote 3: But we are talking about even discussing, say I have two children, what is the fear of discussing, say I have a daughter that is getting a PhD, I think she is more reliable, not necessarily but I may. If I talk about it and put her down there, what's my other daughter going to say? "What you don't trust me, you don't think---" and then it brings up a lot of things that from that point on it can cause dissention and fall out among family members. This has nothing to do with when you are dead, they can fall out. The fear of talking to our children, we are talking about discussing with the ones that are most intimate with us. Our family, our children, our husband. Some people don't want to discuss because they don't want their husband to be in charge and don't want him to know that they don't want him in charge. It is so much that doesn't have to do with outside the family but our own children...We do have control in our own sphere, I have control to sit down and talk with my, I have 3 children, I could sit down and share with my own children if I so choose. But if I don't talk to them because I don't know how one is going to take it. And then like Saundra said, the one that you want to speak for you is not the one that you would want taking care of you because you know that they don't have the patience or skills. So then when one child that you want to speak for you but when you get sick I am going to have to do the caretaking... Why don't we want to.