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AFRICAN AMERICAN MEN'S PROSTATE CANCER KNOWLEDGE AND SELF-EFFICACY FOR INFORMED DECISION-MAKING: A MIXED METHODS STUDY

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AFRICAN AMERICAN MEN'S PROSTATE CANCER KNOWLEDGE AND SELF-EFFICACY FOR INFORMED DECISION-MAKING: A MIXED METHODS STUDY

by

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Barbara K. Haas, Ph.D., R.N. Committee Chair

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AFRICAN AMERICAN MEN'S PROSTATE CANCER KNOWLEDGE AND SELF-EFFICACY FOR INFORMED DECISION-MAKING: A MIXED METHODS STUDY

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A mixed methods study was conducted whereby, the quantitative portion has a randomized control design, in an urban Delaware community to examine the effectiveness of an educational intervention, which included the testimony of an African American (AA) prostate cancer survivor on AA men's (n=98) prostate cancer knowledge and self-efficacy for informed decision making. Guided by Bandura's Social Cognitive theory, participants' prostate cancer knowledge measured by PROCASE and for self-efficacy measured by the Prostate Cancer Screening Self-efficacy scale, were evaluated before and following viewing of the American Cancer Society's prostate cancer video. Participants randomized to the intervention completed evaluations after the intervention. A sample (n=10) from each group participated in their respective focus groups. A control focus group (those who neither watched video or heard speaker) was also evaluated. The MANCOVA, using Pillai's trace, demonstrated a significant effect of the intervention on knowledge and self-efficacy posttest scores, ($V= .28, F_{6,82} = 4.937, p= .000$). Combining a prostate cancer survivor's testimonial with an educational video increases knowledge and self-efficacy among AA men in this urban community.

Chapter One. Introduction

Overview of the Program of Research

Despite research examining various education interventions to improve knowledge of prostate cancer among African American (AA) men, the incidence and mortality rates of AA men with prostate cancer are still greater than rates among Caucasian men. Twenty-four percent of AAs have basic or below literacy skills compared to nine percent of White respondents (AHRQ, 2011). Health literacy has been identified as a growing concern in health care as low health literacy has been linked to poor health outcomes. The American Cancer Society (2016) reports AAs have the highest death rate and shortest survival time compared to any racial or ethnic group in the United States for most cancers. African Americans are diagnosed at later stages of illness and have poorer prognosis. Ultimately, health literacy influences AA health consumers' understanding of disease prevention and management, self-efficacy, perceived susceptibility, adherence to medical protocols, informed consent, and medication administration (Weekes, 2012). African Americans lack knowledge about cancer, combined with fatalistic attitudes and beliefs about cancer, which could account for their delay in seeking medical attention. In spite of the association to poor outcomes, especially among vulnerable populations like AAs and low socioeconomic status health consumers, the definition of health literacy remains ambiguous.

Introduction to Articles

In the initial step of this program of research, health literacy among AA's was explored through a concept analysis. The purpose of the concept analysis was to define health literacy and analyze the current state of the science in health literacy among African

Americans regarding cancer prevention, care, and knowledge. Results of the concept analysis are reported in Chapter 2, *Health Literacy Among African Americans: An Oncology Focus.*

Studies have found a correlation between knowledge of prostate cancer and screening behavior (Ford et al., 2011). Following the exploration of health literacy among AA's, a mixed methods randomized controlled study titled, *African American Men's Prostate Cancer Knowledge and Self-Efficacy for Informed Decision Making: A Mixed Methods Study* was conducted. University Institutional Review Board approval (Appendix A) was obtained prior to study initiation.

Bandura's (1986) Social Cognitive Theory (SCT) provided the theoretical framework for the exploration of research examining the effectiveness of an educational intervention to increase AA men's prostate cancer knowledge and self-efficacy for informed decision-making. The principals of Social Cognitive Theory (Appendix B) considers how both environmental and personal factors interact to influence human behavior. Social Cognitive Theory emphasizes the importance of observing and modeling behaviors, attitudes, and emotional reactions of others so it focuses on learning by observation and modeling. Specifically, the theory posits a triadic reciprocation among the concepts of person, environment, and behavior (Bandura, 1986).

The research explored modeling provided by a community AA prostate cancer lay survivor, which afforded an opportunity to teach new behaviors to other AA men in the community. According to SCT, AA men are more likely to adopt behavior (discussing screening options with a health care provider) if the environmental model (community AA prostate cancer lay survivor) is similar to the observer (AA male), has admired status, and the behavior has functional value (prostate cancer free).

Key community organizations and leaders were contacted to assist with recruitment of participants. Flyers (Appendix C) were also posted throughout the community in barbershops, churches, and community recreational centers to publicize the study. After signed informed consent (Appendix D) was obtained, an envelope with a demographic data sheet (Appendix E) and study instruments was distributed. Survey instruments included the PROCASE pretest and posttest (Appendix F), Prostate Cancer Screening Self-Efficacy pretest and posttest (Appendix G), Self-Efficacy addendum (Appendix H) and an evaluation form (Appendix I). Prior to data collection, permission was obtained for use of the educational video (Appendix J), PROCASE tool (Appendix K), and Self-Efficacy tool (Appendix L).

The qualitative strand of the study utilized focus group discussions for 10-12 participants from each group. The group facilitator, a Registered Nurse and Clinical Instructor, led each focus session, following an interview guide (Appendix M). Findings of the mixed methods research design study are reported in Chapter 3, titled *African American Men's Prostate Cancer Knowledge and Self-Efficacy for Informed Decision-Making: A Mixed Methods Study*. The final chapter in this dissertation provides a summary of the research to date along with a trajectory for future research.

Chapter Two: Health Literacy Among African Americans: An Oncology Focus

Abstract

The purpose of this manuscript is to define the concept of health literacy in an effort to reduce ambiguities between the definitions of health literacy and analyze the current state of the science in health literacy among African Americans in oncology. Databases accessed were CINAHL, EducationSource, MEDLINE, PsychARTICLES, and PsychINFO using keywords *health literacy, among African Americans* or *Blacks and cancer* or *oncology*. Health literacy is a critical issue as low health literacy is associated with worse health outcomes, especially in vulnerable populations like African Americans and low socioeconomic status health consumers. The health literacy of intended audience must be considered when developing educational resources. Findings included an awareness and attention to the health literacy needs of all patients to promote the nursing goal of optimizing health care delivery, especially for the most vulnerable populations. Clarifying the concept of health literacy is an important first step toward actual progress in achieving better health outcomes for everyone. Implications include: nurses will need to assess and understand their patient's health literacy as well as their own. Future research should involve an increased awareness of health literacy among health care providers and more effective communication strategies for people with inadequate health literacy. Health literacy impacts all consumers despite race, age, gender, socioeconomic status, or educational level. While health literacy includes three defining attributes that center around capacity, comprehension, and communication, critical health literacy is an evolving concept that will continue to grow based on need and effective application by health providers.

Keywords: health literacy, African Americans, oncology, concept analysis

Health Literacy Among African Americans: An Oncology Focus

Health literacy is a growing concern in health care as its absence has been linked to poor health outcomes (Cooper, 2011). While the concept of health literacy has been a growing concern in the United States, it has also garnered increased interest internationally (Sorensen et al., 2012). However, the meaning of the term *health literacy* remains ambiguous. What is certain is that inadequate health literacy has been connected to lower levels of cancer awareness, knowledge, screening utilization, and follow-up care (Agho et al., 2012; Evans, Lewis, & Hudson, 2012; McCleary-Jones et al., 2013). Moreover, low socioeconomic status, limited education, and minority race are risk factors for low health literacy and worse cancer outcomes (American Cancer Society [ACS], 2013; Friedman, Corwin, Dominick, & Rose, 2009; Matsuyama et al., 2011).

African Americans have higher rates of cancer health disparities as they are more likely to develop and die from cancer than any other racial or ethnic group (ACS, 2016). As cancer information resources and programs are developed, it is paramount to understand the health literacy levels of intended audiences, especially to address cancer health disparities among African Americans.

Background

While health literacy has become a national priority in the United States (Office of Disease Prevention and Health Promotion [ODPHP], 2015), the definition is still evolving and has not been consistently applied. Earlier definitions of health literacy primarily centered on a patient’s reading and math skills and were patient focused. More recent definitions have expanded to include a broader range of attributes surrounding specific skills necessary to navigate the health care system; to proactively search and access information; to use health information in a way that will promote healthy behavior; and listening and communication skills of the patient and health care provider (National Network of Libraries of Medicine [NNLM], 2017).

Despite variance in the definition of health literacy, there is a consensus that there is a relationship between low health literacy and poor health outcomes (Agho et al., 2012). Low health literacy is linked to higher risk of death; more emergency room visits and hospitalizations; infrequent use of preventative services; poor understanding of medical conditions and treatment that results in non-adherence to medical instructions; and eventually higher morbidity and mortality rates as well as higher health care costs (Agency for Health Care Research and Quality [AHRQ], 2011; Baker, Wolf, Feinglass, & Thompson, 2007). Low health literacy is a major source of economic inefficiency in the US health care system (Vernon, Trujillo, & Rosenbaum, 2007). This 2007 report estimated the cost of low health literacy to the US economy is between $106 billion to $238 billion annually.

Low health literacy interferes with people's ability to search for and use health information, adopt healthy behaviors, and act on important public health alerts, which include cancer screening and other preventative health measures (Bynum et al., 2013). When including age, race, income and education levels, the impact of low health literacy disproportionately affects people of lower socioeconomic status and minority populations (Agho et al., 2012; Ginossar, 2014; Nutbeam, 2008; NNLM, 2017). The National Assessment of Adult Literacy (NAAL) reported Caucasian respondents scored better on the health literacy survey than other ethnic or racial groups as only 9% of Caucasian respondents scored at the lowest level (Below Basic); but 24% of Blacks, 41% of Hispanics, 13% Asians, and 25% of American Indian and Native Alaskan respondents scored at the "below basic" level (Kutner, Greenberg, Jin, & Paulsen, 2006). That same study reports adults living below the poverty level have lower average health literacy than adults living above the poverty threshold. In addition, the NAAL study reports the elderly (over 65 years old) have lower health literacy compared to those less than 65 years old. Health literacy has an impact on health outcomes and contributes to health disparities.

Another factor that may help us better understand health literacy is the role of culture, which has become increasingly recognized as an important concern in communication specific to health literacy (NNLM, 2017). The US Department of Health and Human Services (USDHHS) recognizes that culture affects how people communicate, understand and respond to health information. While health literacy was once viewed as an individual-level construct, it now expands the emphasis beyond individuals to also include groups and identifies health literacy as a "systems issue" (Berkman, Davis, & McCormick, 2010; Rudd, 2010).

In summary, health literacy is a growing concern not only in the US, but also abroad. The definition of health literacy continues to evolve from earlier definitions which emphasized reading and math to current views that incorporate a broader range of attributes such as listening, communicating, using information, and navigating the health care system to make appropriate decisions as described in a systematic review by Sorensen et al. (2012) and a commentary by Berkman et al. (2010). Health literacy concerns the knowledge and competencies of persons to meet the complex demands of health in modern society (Sorensen et al., 2012). Culture and communication are now factors to be considered when trying to understand health literacy. Low health literacy is associated with worse health outcomes and with specific racial and ethnic groups such as African

Americans and low socioeconomic status patients. These factors demonstrate why it is necessary to have a better understanding of health literacy to reduce disparities.

Methods

An electronic search was conducted using the following databases: Cumulative Index to Nursing and Allied Health Literature Complete (CINAHL), EducationSource, MEDLINE, PsychARTICLES, and PsychINFO. The search was limited to key terms *health literacy among African Americans or Blacks and cancer or oncology* from 2010 to 2015. The search was further narrowed to only include scholarly (peer reviewed) journals, which yielded 1,958 hits. The extent of literature found within this subject area spans a broad spectrum, including general health literacy; health literacy tools; health literacy research studies; barriers to cancer screening and care; cancer communication; and research studies in various types of cancer. This paper included articles describing health literacy among African Americans in oncology.

Nursing Significance

With health literacy gaining increased attention and concern from health care professionals, the *Healthy People 2020* initiative of the USDHHS has included health literacy as a pressing new topic, with objectives for addressing it in the next decade (USDHHS, 2010). There have been several other federal policy initiatives that also address the low health literacy issue, including the Affordable Care Act, National Action Plan to Improve Health Literacy, and the Plain Writing Act (NNLM, 2017). While there is a consensus within the health care arena that health literacy is significant and linked to patient outcomes, the fact that it has different meanings to various audiences establishes health literacy as a conceptual problem. Therefore, the definition of the concept, *health literacy*, in the nursing discipline and its impact on vulnerable populations -specifically, African Americans in oncology will be addressed in this analysis.

Health literacy is not only a concern for patients but also for health care professionals who may have poor health literacy skills, such as a reduced ability to clearly explain health issues to patients (Fields, Freiberg, Fickenscher, & Shelley, 2008). An important step towards health disparity reduction is the effective use of social and cultural constructs to communicate about health and health behavior change (Sanders Thompson et al., 2008). According to the American Medical Association (AMA), poor health literacy is a stronger predictor of a person's health than age, income, employment status, education level, and race (NNLM, 2017). Inadequacies in health literacy have been linked to lower levels of cancer awareness, knowledge, screening utilization, and follow up care (Bynum et al., 2013). Low literacy adversely impacts cancer incidence, mortality, and quality of life. For example, cancer screening information may be ineffective; as a result, patients may be diagnosed at a later stage of disease. Nurses are at the forefront of protecting and advocating for better patient outcomes, which are clearly linked to health literacy.

Health Literacy among African Americans

Twenty-four percent of African Americans have basic or below literacy skills compared to 9% of European Americans (AHRQ, 2011). African Americans have the highest death rate and shortest survival compared to any racial or ethnic group in the US for most cancers (ACS, 2016). In addition, African Americans have a higher cancer risk and incidence rate compared to Caucasians (ACS, 2016). For all cancer sites combined, African American men have a 16% higher incidence rate and 33% higher mortality rate compared to Caucasian men. While African American women have a 6% lower incidence rate, they have a 16% higher mortality rate compared to Caucasian women (ACS, 2016). The five-year relative survival rate is lower among African American men and women compared with Caucasians for most cancers at each age and stage of diagnosis (ACS, 2016). Cancer health disparities exist among African Americans such that the government made it one of the foci in the HealthyPeople2020 initiative (ODPHP, 2015). The NAAL study found African Americans have lower health literacy levels compared to Caucasians (Kutner et al., 2006). With health literacy becoming an increasingly growing concept linked to worse health outcomes, it is important that health literacy and health disparities be examined collectively, especially in populations like African Americans with cancer.

Health literacy influences African American health consumers' understanding of informed consent, diseases, self-efficacy, perceived susceptibility, adherence to medical protocols, and medication administration (Weekes, 2012). In many cases, African Americans are not fully informed of their cancer risks and screening options, which contribute to low self-efficacy (Ford et al., 2011; Kendrick, Montgomery, & Outtara, 2009). Low levels of knowledge are associated with low self-efficacy and low rates of participation in prostate, breast and cervical cancer screening (Kendrick et al., 2009; Ford et al., 2011).

Research implies differences in the way African Americans want to receive education may be influenced by specific cultural beliefs which shape attitudes, health perceptions, and self-efficacy and therefore affect behavior (Luque et al., 2010; Odedina et al., 2011). In addition, health literacy directly impacts use of health prevention services (Agho et al., 2012). Specifically, health literacy is known to impact health including health behavior, health outcomes, communication with providers, adherence to treatment regimens, and health care costs such as higher hospitalization rates and less frequent use of preventive health services (McCleary-Jones et al., 2013; Weeks, 2012). Exploring strategies to improve communication from the perspective of African Americans or other low health literacy populations may help clinicians better understand the beliefs in this population.

Concept Identification

Health literacy is a multidimensional concept and consists of different components. The concept has been evolving despite being introduced as early as the 1970's (Simonds, 1974). The early definitions of health literacy were primarily patient (or individual) focused and centered on a patient's reading and math skills. A current and popular definition is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Institute of Medicine [IOM], 2004). The World Health Organization's (WHO) definition of health literacy is a set of social and cognitive skills that determine the motivation and ability of individuals to gain access to understand and use information in ways that promote and maintain good health (WHO, 1998). Finally, the AMA defines health literacy as the constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment, such as the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials (AMA, 1999). The concept of health literacy is broadening to include use of a complex and interconnected set of skills and abilities, such as reading and acting upon written health information, appropriately taking steps towards health promotion, communicating needs to health care providers, and understanding health instructions (Berkman et al., 2010; Mancuso, 2008; Sorensen et al., 2012).

Most health literacy conceptual models consider key components and identify individual and system-level factors that influence a person's level of health literacy (Nutbeam, 2008; Sorensen et al., 2012). As awareness of health literacy becomes more popular, the literature identifies additional dimensions of health literacy. The IOM (2004) report considers cultural and conceptual knowledge, listening, speaking, arithmetic, writing, and reading skills as the main components of health literacy. Baker (2006) divides health literacy into health-related print literacy and health related oral literacy, while Paashe-Orlow and Wolf (2010) distinguish between listening, verbal fluency, memory span and navigation.

Concerning health literacy as defined from within systems, it is a dimension beyond individual competencies. Nutbeam (2008) distinguishes three types of health literacy: Level I, functional health literacy; Level II, interactive health literacy; and Level III, critical health literacy. Functional health literacy refers to an ability to apply basic skills in reading and writing that are necessary to function effectively in everyday situations, such as reading medication labels (Nutbeam, 2008). Interactive health literacy involves the use of cognitive skills and literacy skills together with social skills than can be used to actively participate in everyday situations, extract information and determine meaning from different forms of communication, and apply this to various circumstances. Finally, critical health literacy incorporates the ability to evaluate health issues, determine challenges and advantages of specific issues, recognize the potential benefit of a particular strategy and apply this information to life events. Manganello (2008) includes media literacy as the ability to critically evaluate media messages.

Public health literacy is a third perspective of health literacy identified in the literature. This conceptualization concerns the knowledge, skills and engagement that groups of individuals possess to address the public health of their community (Freedman et al., 2009). Mancuso (2008) emphasizes heath literacy is a process that evolves over a person's lifetime and identifies the attributes of health literacy to be capacity, comprehension, and communication. Public health literacy is complementary to individual health literacy, and outcomes include a community's understanding of public health messages as well as the skills to evaluate and participate in civic action related to health care issues (Berkman et al., 2010).

While the concept of health literacy has expanded in scope and depth over the past 40 years or so, some specialty areas within health care identify health literacy as a set of individual capacities that allow a person to acquire and use new information. Other specialties conclude that health literacy is a dynamic state of an individual during a health care encounter and that an individual's health literacy may vary depending upon the health care concern, the provider, and the environment in which they are receiving care (Baker et al., 2007; Freedman et al., 2009; Martensson & Hensing, 2012). Also, definitions of health literacy have begun to embrace a more community conceptual model with an appreciation for the role of communication, culture, as well as a skill set for the use of technology as a component of health literacy skills (Hepburn, 2012; Mancuso, 2008; McCleary-Jones et al., 2013; Nutbeam, 2008).

Defining Attributes

From the literature review, three defining attributes of health literacy identified were as follows:

1. ability to obtain and understand health information,
2. ability to use health information to make health decisions,
3. ability to communicate with understanding.

First, the ability to obtain and understand or interpret health information is necessary for a person to be health literate. That person should be able to gather, analyze, and evaluate health information. It is necessary for an individual to be able to read and comprehend written and verbal health instructions such as prescription bottle labels, appointment slips, or discharge/post-operative instructions. A person may be literate within the context of familiar terms or content but functionally illiterate when required to comprehend unfamiliar subject matter such as vocabulary or concepts encountered in health care settings (Kripalani et al., 2010).

Second, ability to use health information to make decisions is essential to the health literate individual. It is not enough to seek and comprehend health information, but it is necessary make appropriate health decisions and act on health care information obtained (Baker, 2006; Mancuso, 2008). The effective use of health information is critical to empowerment (Edwards, Wood, Davies, & Edwards, 2012). As people with better health literacy may be more empowered and also have better health outcomes, it is expected that improvements in health literacy over time should lead to better self-management, better health outcomes, more active involvement in health decision-making, and greater abilities to manage health conditions (Edwards et al., 2012; Weekes, 2012).

Third, communication is how thoughts, messages, or information are exchanged and includes speech, signals, writings, or behavior (Mancuso, 2008). The characteristics of effective health communication encompass accuracy, availability, balance, consistency, cultural competence, evidence base, reach, reliability, repetition, timeliness, and understandability which can take place in a variety of forms (written, verbal, virtual, or via Internet) so individuals must have these essential skills to be health literate (Mancuso, 2008).

In addition, the literature describes “critical health literacy” as acting individually or collectively to improve health through the political system or membership of social movements (Sykes, Wills, Rowlands, & Popple, 2013). This has been found to be a unique concept and could be argued as a fourth defining attribute to health literacy (Martensson & Hensing, 2012).

Antecedents and Consequences

The antecedents, or pre-existing factors, necessary for health literacy to occur, are the ability to read and numeracy skill. Reading skill includes a complex array of meta-cognitive behaviors, such as focusing attention, using contextual analysis to understand new terms, using text structure to assist in comprehension, word recognition, and organizing and integrating new information (Baker, 2006; Sorensen et al., 2012). Numeracy skill is the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, and probabilistic health information needed to engage in and manage mathematical demands of a range of situations in adult life (Institute of Education Sciences [IES], n.d.).

Consequences identified in the literature for health literacy include increased health knowledge, patient empowerment, lower hospitalizations, decreased use of health services, improved health outcomes, and lower health care costs (Baker, 2006; Sorensen et al., 2012; Vernon et al., 2007). Nutbeam (2008) distinguishes between individual and community or social benefits of health literacy. From the perspective of individual benefits, functional health literacy leads to improved knowledge or risks and health services and compliance with prescribed actions; interactive health literacy leads to an improved capacity to act independently, an improved motivation and increased self-confidence; and critical health literacy leads to improved individual resilience to social and economic adversity (Nutbeam, 2008). From the perspective of community and social, functional health literacy increases participation in population health programs; interactive health literacy enhances the capacity to influence social norms and interact with social groups; and critical health literacy improves community empowerment and enhances the capacity to act on social and economic determinants of health (Nutbeam, 2008).

Empirical Referents

The concept of health literacy could be measured several ways in the nursing research. The Test of Functional Health Literacy in Adults (TOFHLA) was developed in 1995 to be used by health care providers and researchers to measure health literacy in adults (Edwards et al., 2012). It focuses on reading comprehension. An empirical referent of health literacy is a score of 75-100 on the TOFHLA. Another tool called the Rapid Estimate of Adult Learning in Medicine (REALM) focuses on reading ability. These tools were later shortened and referred to as S-TOFHLA and REALM-R. A newer tool is The Rapid Estimate of Adult Literacy in Medicine Short Form (REALM-SF). It is a 7-item word recognition test to provide clinicians with a quick assessment of patient health literacy. The REALM-SF has been validated and field tested in diverse research and has excellent agreement with the 66-item REALM instrument in terms of grade-level assignments settings (Arozullah et al., 2007).

Another tool was developed to measure an aspect of health literacy, which evaluated an individuals' reading comprehension in a medical context. The Short Assessment of Health Literacy – Spanish and English (SAHL-S&E) is an 18-item assessment of health literacy in people who speak English and Spanish. The SAHL-S&E is reported to have good reliability and validity in both languages (Lee, Bender, Ruiz, & Choi, 2010).

An additional test, the Health Activities Literacy Scale (HALS), which was developed in the United States by the Educational Testing Service, was designed to assess activities that are not necessarily confined to traditional healthcare settings such as surgical centers, hospitals, and clinics, but those that take place in the home, at work or in the community (Edwards et al., 2012). The HALS is considered a more comprehensive tool compared to the S-TOFHLA and REALM-R because it includes different health-related competencies in five domains – health promotion, health protection, disease prevention, health care and maintenance, and systems navigation (Nutbeam, 2008). Some concerns with the HALS is that its properties are unknown, and the full-length test takes up to one hour to administer.

Another validated instrument for assessing patient health literacy is the Single Item Literacy Screener (SILS). This is a single item instrument designed to identify patients who need help with reading health-related information. The instrument asks one question "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" with possible responses ranging from "1" (never) to "5" (always) (Morris, Maclean, Chew, & Littenberg, 2006). The authors identified the cut-off point as "2" in order to capture all patients potentially in need of assistance (Morris et al., 2006).

Finally, the 25-item Health Literacy Skills Instrument (HLSI) was developed as a skills-based tool to measure health literacy (McCormack et al., 2010). The skills include the ability to read and understand text and locate and interpret information in documents (print literacy), to use quantitative information (numeracy), to listen effectively (oral literacy), and to seek information through the Internet (navigation) (Bann, McCormack, Berkman, & Squiers, 2012). This tool also has been validated in a shorter version called the HLSI-Short Form or HLSI-SF. There are a number of validated instruments available for assessing patient health literacy. Some are preferred for research settings and others are preferred for clinic settings. As the health literacy concept evolves, the measurement tools will need to evolve accordingly.

Conclusion and Recommendations

Health literacy is a reoccurring theme as nurses try to identify appropriate educational interventions to meet the needs of specific patient populations. Health literacy influences African American health consumers' understanding of informed consent, disease prevention and management, self-efficacy, perceived susceptibility, adherence to medical protocols, and medication administration (Weekes, 2012). Health literacy includes three defining attributes that center around capacity, comprehension, and communication.

It is important for nurses to assess their patient's health literacy as well as their own understanding to maintain effective communication. It is also important for nurses to understand that social and educational levels have little relationship to health literacy. Future research will aim at increased awareness of health literacy among health care providers, intensive analysis of improvement strategies, and more effective communication strategies for people with inadequate health literacy skills (Martensson & Hensing, 2012).

The National Action Plan to Improve Health Literacy seeks to engage organizations, professionals, policy makers, communities, individuals, and families in a linked, multisector effort to improve health literacy. The plan is based on the principals that (1) everyone has the right to health information that helps them make informed decisions and (2) health services should be delivered in ways that are understandable and beneficial to health, longevity, and quality of life. This vision informs a society by providing everyone with access to accurate and actionable health information; delivers person-centered health information and services; and supports lifelong learning skills to promote good health (USDHHS, 2010). Awareness and attention to health literacy needs of all patients will promote the nursing goal of optimizing health care delivery, especially for the most vulnerable populations. Clarifying the concept of health literacy is an important first step toward actual progress in achieving better health outcomes for everyone.

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Chapter Three. African American Men's Prostate Cancer Knowledge and Self-Efficacy for Informed Decision-Making: A Mixed Methods Study

Abstract

A mixed methods study was conducted whereby the quantitative portion has a randomized control design, in an urban Delaware community to examine the effectiveness of an educational intervention, which included the testimony of an African American (AA) prostate cancer survivor on AA men's (n=98) prostate cancer knowledge and self-efficacy for informed decision making. Guided by Bandura's Social Cognitive theory, participants' prostate cancer knowledge measured by PROCASE and for self-efficacy measured by Prostate Cancer Screening Self-efficacy (PCS) were evaluated before and following viewing of the American Cancer Society's prostate cancer video. Participants randomized to the intervention completed evaluations after the intervention. A sample (n=10) from each group participated in their respective focus groups. A control focus group (those who neither watched the video or heard speaker) was also evaluated. The MANCOVA, using Pillai's trace, demonstrated a significant effect of the intervention on knowledge and self-efficacy posttest scores, (V= .28, $F_{6,82}$ = 4.937, p= .000). Combining a prostate cancer survivor's testimonial with an educational video increases knowledge and self-efficacy among AA men in this urban community.

Keywords: African American men, prostate cancer knowledge, self-efficacy, screening

African American Men's Prostate Cancer Knowledge and Self-Efficacy for Informed Decision-Making: A Mixed Methods Study

African American (AA) men are diagnosed and die of prostate cancer more than any other racial or ethnic group (American Cancer Society [ACS], 2016). The ACS (2016) estimated one in six AA men will be diagnosed with prostate cancer in their lifetime compared to an estimated one in eight Caucasian men. During 2008-2012, the average annual prostate cancer incidence rate among AA men was 208.7 cases per 100,000 men, which is 70% higher than the rate in Caucasian men (123.0 cases per 100,000 men) (ACS, 2016).

Prostate cancer is the second leading cause of cancer death in AA men with an estimated 4,450 deaths expected in 2016 (ACS, 2016). The mortality rate for prostate cancer is 2.4 times higher in AA men than in Caucasian men (ACS, 2016). During 2008-2012, the average annual prostate cancer mortality rate among AA men was 47.2 cases per 100,000 men and 19.9 cases per 100,000 for Caucasian men.

Research examining various educational interventions such as pamphlets, videos, and the internet to assess and improve knowledge of prostate cancer among AA men has been conducted (Santos et al., 2014; Sheridan, 2012; Ukoli et al., 2013). Despite this, the incidence and mortality rates of AA men with prostate cancer continue to be higher when compared to Caucasian men. Though education alone may not alter the incidence of prostate cancer among AA men, earlier screenings may contribute to earlier diagnosis and a decrease in mortality from the disease. Over the last several years, there has been disagreement over prostate cancer screening guidelines. Thus, recommendations are conflicting and controversial which contributes to confusion for men and their families (ACS, 2016).

Several researchers have noted the need for development and utilization of targeted educational interventions to meet the diverse health care needs of people in this country (Saunders et al., 2013; Song, Hamilton, & Moore, 2012; Vijaykumar, Wray, Jupka, Clarke, & Shahid, 2013). Given the higher incidence and mortality rates compared to other racial and ethnic groups, educating AA men on prostate cancer screening options is important, but there is also a need for targeted educational interventions that are culturally sensitive and balanced to meet the specific needs of AA men (Patel et al., 2012; Ross et al., 2011; Song et al., 2012).

To date, limited studies (Boehm et al., 1995; Vijaykumar et al., 2013; Weinrich et al., 1998) evaluated a peer-educator method intervention that included a testimony in support of prostate cancer education and screening options delivered by an AA prostate cancer survivor. Little is known about the effectiveness of combining an AA prostate cancer survivor's testimonial with a prostate cancer educational video that addresses core questions and concerns men have regarding their prostate cancer screening options.

In addition, AA men have expressed a lack of self-efficacy or confidence in their ability to communicate effectively with their physician regarding early detection prostate cancer decision-making (Ford et al., 2011; Nielson, Mehlsen, Jensen, & Zachariae, 2013; Olugbeminga & Tataw, 2013). Self-efficacy has been demonstrated to be key in changing health behaviors among other populations including women and cervical cancer screening (Kessler, 2012; Mo, Choi, & Kim, 2013), and among non-Hispanic White males regarding colorectal cancer screening (McQueen et al., 2010). It has not been well-studied in the AA male population in regards to prostate cancer screening. This study addressed these gaps through a convergent parallel mixed methods study design that included a randomized pretest posttest quantitative strand and a focus group qualitative strand.   The purpose of this mixed methods study was to evaluate the effectiveness of an educational intervention on African American men's prostate cancer knowledge and self-efficacy for informed decision-making.

Review of Literature

The current prostate cancer screening or "early detection" guidelines vary by major professional organizations. The National Comprehensive Cancer Network (NCCN) supports continued use of prostate specific antigen (PSA) testing for the early detection of prostate cancer among informed, healthy men in certain age groups (NCCN Guidelines Prostate Cancer Early Detection, 2015). The NCCN guidelines recommend informed testing beginning at age 45 for a baseline with repeat testing at specific intervals depending on prostate specific antigen (PSA) value (NCCN Guidelines Prostate Cancer Early Detection, 2015). However, the recommendation does not address high-risk populations, defined as AA men or men with a first-degree relative with prostate cancer. The NCCN points out that prostate cancer screening has been primarily studied in Caucasian men; data on diverse and high-risk populations are lacking.

The American Urological Association (AUA) updated its recommendations for screening to include two major changes. The AUA first notes that while routine screening in men between ages 40 to 54 years is not recommended, for men younger than age 55 years at high risk (i.e., AA men or positive family history), decisions regarding prostate cancer screening should be individualized. Secondly, the AUA recommends shared decision making for men age 55 to 69 years basing PSA screening and proceeding on the man's values and preferences (American Urological Association, 2013).

The controversy regarding PSA screening was likely initiated by the recommendation by the United States Preventative Services Task Force (USPSTF) in May 2012 that routine PSA screening no longer be done. Since AA men are disproportionately affected by higher prostate cancer incidence and mortality, the USPSTF recommendation to eliminate routine PSA testing significantly impacts AA men. The revised recommendations also increase the need for AA men to understand their prostate cancer screening options and engage in informed decision-making. However, understanding screening options may not be enough as AA men have traditionally been reluctant to seek health care (Song, Hamilton, & Moore 2012) and more specifically, are hesitant to initiate discussions around preventatives services such as PSA screening (Pedersen, Ames, & Ream, 2012; Sheridan et al., 2012).

Prostate Cancer Knowledge

Studies have found a correlation between knowledge of prostate cancer screening and screening behavior (Ford et al., 2011; Odedina et al., 2011). The most significant gap in the literature is a lack of randomized control trials that explicitly address targeted interventions to increase prostate cancer screening knowledge and provide information for informed decision-making among AA men (Patel et al., 2012; Ross et al., 2011; Vijaykumar et al., 2013). Two themes were evident throughout the literature related to prostate screening among minority men. First, delivering culturally sensitive care as well as demonstrating culturally appropriate communication afforded health care providers an opportunity to address specific race and ethnic health disparities (Vijaykumar et al., 2013).

Secondly, prostate cancer information written in technical language may discourage men from engaging in healthy lifestyles and screening practices (Ross et al., 2011).

Self-efficacy for Prostate Screening

Self-efficacy for prostate screening is conceptually defined as an ability to perform behaviors to screen and detect prostate cancer (Boehm et al., 1995). There has been evidence of applying Bandura's (1986) Theory of Self-Efficacy in oncology suggesting relationships between self-efficacy and cancer prevention and self-efficacy and adaptation to cancer (Boehm et al., 1995; Zhang et al., 2014). In many cases, AA men are not fully informed of their prostate cancer risks and screening options, which can lead to low self-efficacy (Ford et al., 2011; Song et al., 2012). Low levels of knowledge are associated with low self-efficacy and low rates of participation in prostate, breast and cervical cancer screening among underserved populations like AA men, Mexican American and sheltered women (Ford et al., 2011; Kessler, 2012).

Research suggests differences in the way AA men want to receive education may be due to cultural variances and therefore affect behavior (Odedina et al., 2011). The literature suggests because of the higher incidence and mortality rates of prostate cancer among AA men, there is a need for targeted educational materials that are culturally sensitive and balanced (Patel et al., 2012, Song et al., 2012; Vijaykumar et al., 2013).

At-risk populations, such as AA men and minorities, need targeted educational materials that are developed according to their specific needs and concerns. Cultural beliefs and values such as cancer fatalism, religion and spiritualism, temporal orientation and acculturation affect AA men's health beliefs, assumptions and behavior (Odedina et al., 2011). It is important that AA men receive educational information to which they can relate and is meaningful to them.

Theoretical Model

Bandura's (1986) Social Cognitive Theory (SCT) provided the theoretical framework for this study. The theory considers how both environmental and personal factors interact to influence human behavior. Specifically, the theory posits a triadic reciprocation among the concepts of person, environment, and behavior (Bandura, 1986).

According to Bandura (1986), SCT emphasizes the importance of observing and modeling behaviors, attitudes, and emotional reactions of others so it focuses on learning by observation and modeling. Modeling provided by a community AA prostate cancer lay survivor affords an opportunity to teach new behaviors to other AA men of the community. So, the AA men are more likely to adopt a behavior (discussing screening options with a health care provider [HCP]) if the environmental model (community AA prostate cancer lay survivor) is like the observer (AA male), has admired status, and the behavior has functional value (prostate cancer free).

Self-efficacy refers to the learner's self-confidence in their ability to perform a specific behavior (Bandura, 1986). Bandura argues self-efficacy, as a component of person, is influenced through four sources: enactive mastery, vicarious experience, verbal persuasion, and physiological state.

In this study (Figure 1), the participants (AA men) come with already formulated attitudes and beliefs about cancer among their population, that shape their confidence (self-efficacy) in discussing prostate cancer screening options appropriate for them (representing person). African American men, as part of a social or cultural group, are influenced by a lay survivor's testimony (representing environment). The actions of the AA men deciding and making informed decisions regarding prostate cancer screening (discussions with a HCP) represent behavior. The specific principles related to this study are role modeling and vicarious reinforcement as they provide an opportunity to teach new behaviors to this population.

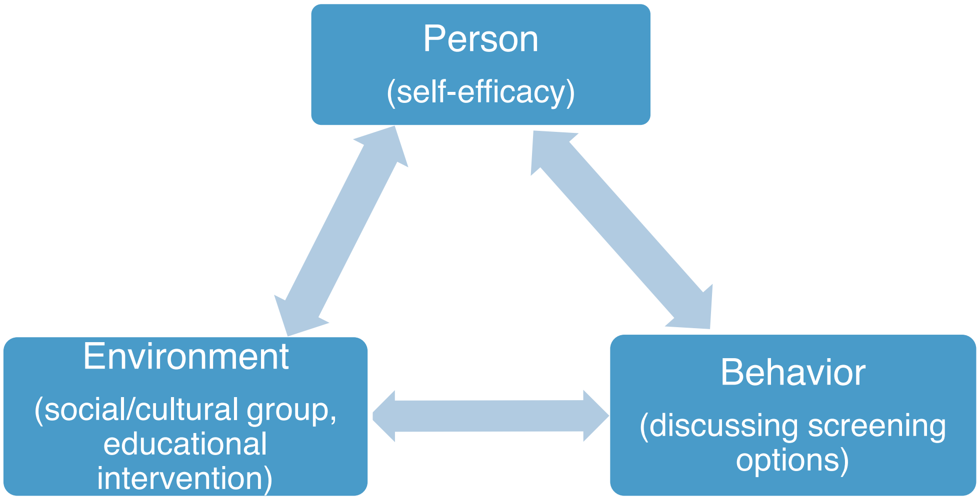

Figure 1. Study Variables Embedded into Social Cognitive Theory

The proposed study was an educational intervention aimed at increasing prostate cancer knowledge and self-efficacy for informed decision-making of AA men by combining a standard prostate cancer education video with a testimonial presentation from a community prostate cancer lay survivor.

The outcome variables for this study included (1) prostate cancer knowledge and (2) self-efficacy for informed decision-making. Cancer knowledge is conceptually defined as the extent of understanding conveyed about cause, type, progress, symptoms, and treatment of cancer (Ford et al., 2011). Prostate cancer knowledge is conceptually defined as the cancer knowledge specifically related to prostate cancer. It includes information such as incidence, mortality and risks of prostate cancer for AA men, treatment effects, explanation of PSA testing, digital rectal examination (DRE), and significance to understanding prostate cancer screening options which was operationally defined by scores on the Prostate Cancer Screening Education (PROCASE) Knowledge Index (Radosevich et al., 2004).

Self-efficacy, conceptually defined as the study participant (AA man) believing he is capable of and equipped with the tools (i.e., prostate cancer knowledge, communication skills, or decision making skills) necessary to make informed decisions regarding prostate cancer screening options was operationally defined by scores on the Prostate Cancer Screening Self-Efficacy (PCS) scale (Boehm et al., 1995)

Research Hypotheses and Questions

Based on SCT, the following research hypotheses were tested:

1. African American men, ≥35 years receiving an educational intervention presented by an AA prostate cancer survivor coupled with viewing a prostate cancer educational video, will report higher prostate cancer screening knowledge than those who only view the video.
2. African American men, ≥35 years, receiving an educational intervention presented by an AA prostate cancer survivor coupled with viewing a prostate cancer educational video, will report higher self-efficacy for informed decision-making than those who solely view the video.

A qualitative strand explored participants' understanding of appropriate prostate cancer screening options and confidence in discussing prostate cancer screening options with a HCP. The research question explored included the following:

1. What are the AA men's understanding and confidence in determining and discussing prostate cancer screening options with an HCP?

Design

A convergent parallel mixed methods design was used with quantitative and qualitative data collected and analyzed simultaneously. Results were merged into an overall interpretation (Creswell & Plano Clark, 2011). The quantitative strand included an experimental pretest posttest control group design to explore the effect of a prostate cancer educational video followed by a testimonial presentation by a community prostate cancer lay survivor on knowledge and self-efficacy for informed decision-making, compared with an educational video alone.

The qualitative strand utilized three focus groups (video only, video + speaker, and no video or speaker) to explore participants' understanding of and perceived confidence in discussing prostate cancer screening options with a HCP. The rationale for choosing this research design was that while quantitative data can demonstrate an increase in knowledge and/or self-efficacy for informed decision-making as determined by survey scores, obtaining qualitative data could provide insight into the participants' perceptions and preferences towards prostate screening educational interventions not known from instrument scores.

Methods

Sample and Setting

A convenience sample of AA men, ≥ 35 years, living in the Delaware area (Delaware, New Jersey, and Pennsylvania) was targeted. Inclusion criteria included: 1) male; 2) self-identified AA; 3) ≥ 35 years; 4) no history of prostate cancer; 6) able to see and hear and; 6) understands spoken and written English. The lower age limit of 35 years was selected because many AA men are offered prostate cancer screening beginning at age 40. Educating men close to this age will provide them with the tools necessary to make an informed decision regarding their prostate cancer screening options. Thirty-five years old was also the minimum age Allen, Kennedy, Wilson-Glover, and Gilligan (2007) chose for participants in a similar study. Recruitment sites included local churches, barbershops, supermarkets, men's fraternities, and community centers. The educational intervention took place on two occasions between December 2015 and January 2016; the first was held at a local church while the second took place at a local barbershop in the same community as the church.

Quantitative. Based on a power analysis using power of .80, an alpha of .05, and a medium effect size (0.60), 44 participants per group were required (Polit & Beck, 2012). A 10% oversampling was done to account for attrition during the intervention, resulting in a minimum sample size of 96. The medium effect size was based on previous studies (Vijaykumar et al., 2013; Zhang et al., 2014).

Qualitative. Three focus groups were conducted. Two focus groups, held on the day of the educational intervention, each included a subset of 10 men randomly selected from their assigned educational group. A third focus group, comprised of 10 men who did not participate in the educational intervention, was also recruited. A subset was solicited to keep the size of the focus group manageable.

Instruments

Quantitative. Prostate cancer screening knowledge was measured pre and post interventions using the Prostate Cancer Screening Education (PROCASE) Knowledge Index. PROCASE Knowledge Index is a 10-item true-false questionnaire that includes three domains of knowledge: natural history of prostate cancer and risk factors (items 1-5); PSA testing accuracy and diagnostic tests (items 6-8); and treatment efficacy and complications (items 9-10) (Radosevich et al., 2004; Ross et al., 2010). Correct answers, coded as "1", are summed for a total PROCASE score, ranging from 0 – 10 with higher scores indicating greater knowledge (Radosevich et al., 2004).

Validity of PROCASE was established through content, construct, and criterion methods. Experts from the original research team agreed that the knowledge items made sense at face value and measured critical domains for being informed about prostate cancer screening choices (Radosevich et al., 2004). For convergent validity, the researchers hypothesized a positive association between knowledge and the respondent's level of formal education, history of PSA test results, and exposure to prostate cancer screening education materials (Radosevich et al., 2004). In evaluating criterion validity, the researchers compared responses of the experts to the scoring rules for the knowledge items (Radosevich et al., 2004). Reliability of PROCASE was established in a sample of 1,152 at-risk men with an acceptable level of reliability as determined by a reported Kuder-Richardson 20 value of 0.68 (Radosevich et al., 2004).

Prostate cancer screening self-efficacy was assessed using the Prostate Cancer Screening Self-Efficacy (PCS) scale. The PCS is a four-item, 5-point Likert –type scale that measures AA men's expectancy that they are capable of performing behaviors required to screen for and to detect prostate cancer (Boehm et al., 1995). Scores range from 4 to 20 with higher scores indicating greater self-efficacy.

Content validity was enhanced by incorporating a review of the literature identifying critical prostate cancer screening behaviors; consulting national experts on content and format; consulting doctors and nurses with expertise in prostate cancer instrument development; and pretesting and revising the tool after focus groups of older AA men. The internal reliability of the scale using Cronbach's alpha was moderate to high at .74 pretest and .86 posttest in previous study (Boehm et al., 1995). Additional questions focusing on informed decision-making were included at the end of the PCS scale as a Self-efficacy addendum.

The estimates for internal consistency reliability, Kuder-Richardson-20 in this sample on 98 AA men for the pretest PROCASE were 0.531 and 0.729 for the posttest PROCASE questionnaire. Reliability estimates for the PCS scale were 0.865 for the pretest and 0.887 for the posttest respectively. Additionally, Cronbach's alpha coefficients for internal consistency reliability for the PCS pretest and posttest were 0.940 and 0.887 respectively.

Qualitative. A focus group discussion guide (Appendix M) addressed the participants' prostate cancer knowledge and confidence in their ability to discuss prostate cancer screening options appropriate for them with a HCP.

Procedures

Prior to study initiation, The University of Texas at Tyler Institutional Review Board approval was obtained. Study flyers inviting participants were displayed throughout community organizations in New Castle County, Delaware (e.g. church bulletins, barbershops, billboards at supermarkets, banks, and convenience stores). Participants had the option of calling the local telephone number listed on the flyer to hear additional study information or ask questions. Fraternal organization member lists with contact information provided by the presidents of each organization were also used to invite participants. As a token of appreciation for participation, five gift cards worth $10 each were offered through a drawing held following completion of the quantitative posttests and following each focus group.

The intervention took place at a church in Wilmington, DE and was repeated the following month at a local barbershop to obtain the minimum number of 96 participants. Upon arrival, participants were introduced to the study and consented by the principal investigator (PI) before receiving a color-coded envelope that determined group assignment. The decision of how participants would receive color coded envelopes was determined by altering the two color coded envelopes of manila and white as the participants completed their consent. Half were assigned to an educational intervention that consisted only of watching a professionally produced multicultural instructional video aimed at men (video only group). Half were assigned to an experimental group who watched the same video and then participated in a session with an African-American prostate cancer survivor, who provided testimonial and answered questions from the participants (video speaker group).

A number on each envelope was assigned as the participant's confidential study number. All documents and study forms within each packet included this unique study number. The color-coded envelopes included a demographic survey, PROCASE pretest (on white paper) and posttest (on blue paper), PCS scale pretest (on white paper) and posttest (on blue paper), and a program evaluation sheet. A raffle ticket was given to each participant as they received their color-coded envelope to ensure a chance of winning as the number of packets could exceed the number of persons who came to the event.

For the qualitative focus groups, every third person on the sign in sheet was selected to participate in their perspective group's (video only or video + speaker) focus group session for a total of 10 men. The participants in the control focus group (no video or speaker) were selected by the first ten men who voluntarily signed consent after explanation of study as this focus group discussion took place when the study was repeated.

Data Collection

Following group assignment, the men gathered in a large hall where all participants viewed the prostate cancer educational video after completing demographic sheet and pretest for the PROCASE and PCS tools. Upon conclusion of video, all participants with white colored envelopes were escorted to one of two other private rooms. In one room, the men completed their posttests for PROCASE and PCS as well as the evaluation form and were dismissed. In the other private room, the focus discussion for the video only group took place for the 10 participants. These participants completed their posttest and evaluations upon completion of group discussion. Meanwhile, in the large hall where the video was shown, the AA prostate cancer survivor began his testimonial. The PI proctored the testimonial ensuring the speaker adhered to only sharing his story and not making recommendations regarding PSA testing or treatment, or providing any other specific direction to the participants. The PI completed three previous one-on-one sessions with AA prostate cancer survivor listening to his testimony and experiences of prostate cancer.

Following the testimonial, participants completed posttest and evaluations except for the 10 participants staying for the focus group discussion (video speaker group); these 10 were escorted to a private room where the group discussion took place. Focus group participants completed posttest and evaluations following the discussion. The focus group participants were initially selected by their placement on the sign in sheet as every 3rd person was chosen; however, at the time of focus group discussion, some men left following the video or speaker testimonial so the group was asked for volunteers until 10 men committed.

All focus groups were led by the same trained AA male research assistant using the focus group discussion guide. The control (no video or speaker) focus group was held the following month due to limited number of participants at the originally scheduled date and location. The research assistant (RA), a male Nigerian-born registered nurse in his late 30s with experience working in research and clinical settings, facilitated all focus group discussions. A trained AA male served as the scribe during the focus group sessions, recording notes and overseeing facilitation of discussion. The scribe is a Master's prepared family therapist with over twelve years conducting group therapy. Both assistants completed ethics training with human subjects before participation and were trained in the study protocol. A Nigerian-born male facilitator was utilized to allow the participants to be more relaxed and open to discussion and participation as opposed to having a female present. Focus groups were audio-recorded using the Olympus digital voice recorder, model VN-7200.

Only 52 of the required 96 sample participated upon conclusion of the study on the originally scheduled day so the study was repeated 3-weeks later at a barbershop within a two-mile radius of the original location. At this time, a control focus group (no video or speaker) also took place. The same RA and scribe were present for the third focus group and repeat interventional sessions (video only and speaker testimonial) for a total of 46 participants.

Analyses

All data were entered into SPSS, version 22.0. Descriptive analyses using means, frequencies and percentages were conducted to examine sample characteristics and distribution. Multivariate analysis of covariance (MANCOVA) with pretests as covariates was used to test the study hypotheses, which examined whether the intervention demonstrated a statistical difference on the participants' prostate cancer knowledge and self-efficacy for informed decision-making.

The audio-recorded focus group sessions were of poor quality; much of the groups' conversation were inaudible and unable to be transcribed. However, hand written notes taken by the scribe during the focus group discussions were incorporated to identify concerns expressed by participants. Therefore, qualitative data were analyzed by examining the combination of the available audio recordings and handwritten notes from the focus group scribe. The handwritten notes were read by PI, reviewed and discussed with the scribe and RA and cross referenced with available audio-recordings for verification.

Results

Sample

The total number of participants who completed all pretests and posttests was *N*=98 (control group, *n*=10; video group, *n*=46; video and speaker group, *n*=42). Ages ranged from 35 to 74 years, with a mean age of 48.82 years (±9.06). A majority of the participants were educated, employed, and had an annual income exceeding $25,000. The sample comprised an equal number of married (*n*=46) and unmarried men (*n*=47). Detailed demographics are seen in Table 1.

Table 1

Demographic Characteristics of the Study Sample (N=98)

Variable	*N*	*Percentage*	*P value*
Age			.153
35-44	34	34.8	
45-54	40	40.8	
55-64	16	16.2	
65-74	8	8.1	
Household income per year*			.317
Less than 25,000	8	8.2	
Between 25,000 – 75,000	50	51.5	
75,000 and higher	39	39.8	
Marital Status			.155
Married	46	46.9	
Not married	47	48.0	
Not married living w/partner	5	5.1	
Employment status*			.276
Full-time	78	79.6	
Part-time	11	11.2	
Not working	8	8.2	
Education*			.045**
Did not complete high school	5	5.1	
Completed high school	33	33.7	
Completed courses beyond high school	59	60.2	
Health Insurance			.989
Private	76	77.6	
Government	15	15.3	
No health insurance	7	7.1	
Talked with HCP regarding PC screening in past 12 months			.014**
Yes	34	34.7	
No	62	63.3	
Had prostate cancer screening past 12 months*			.027**
Yes	23	23.5	

No	73	74.5	
Family history of prostate cancer			.343
Yes	16	16.3	
No	80	81.6	

Note. *Missing data, **Significant *p*<.05, two-tailed

Chi Square analysis was conducted to determine demographic differences among groups. There were no significant differences on the major demographic variables with two exceptions. The men in the combination video and speaker group were more likely (*p*=.031) to have had a conversation with their health care provider (52.4%) in the previous 12 months compared with the video only (21.7%) or the control (20.0%). Secondly, the men in the combination video and speaker group were also more likely (*p*=.027) to have had education beyond high school (71.4%) compared with 50.0% of video only group and 60% of the control group.

Table 2

Chi Square Analysis Among Demographic Sub-Groups (N=98)

	Age	*Income*	*Marital Status*	*Employment Status*	*Education*	*Health Insurance*
Spoke with HCP <12months	.524	.030**	.000**	.409	.021**	.304
Prostate Cancer Screening <12months	.567	.120	.002**	.246	.246	.500
Family History of Prostate Cancer	.708	.046**	.454	.452	.452	.945

**Significant *p*<.05, two-tailed

Chi square analysis among demographic sub-groups was analyzed using crosstabs based on age, household income, marital status, employment status, education, and health insurance with those who spoke with a health care provider about prostate cancer screening within past 12 months, those who had prostate cancer screening within the past 12 months, and those with a family history of prostate cancer. Probability values are listed in Table 2.

Hypothesis 1

Hypothesis one, which predicted the study participants who viewed the prostate cancer educational video and heard the prostate cancer survivor's testimonial would demonstrate higher prostate cancer screening knowledge, was supported by MANCOVA with pretest scores as covariate. The MANCOVA, using Pillai's trace, demonstrated a significant effect of the intervention on posttest scores, (V= .28, $F_{6,182}$ = 4.937, p= .000). In addition, separate univariate ANOVAs on the outcome variables revealed significant treatment effects on the PROCASE posttest calculated score for prostate cancer knowledge, ($F_{2,95}$=9.646, p=.000). In addition, the group means and standard deviations of the PROCASE posttest for each group are displayed in Table 3.

Table 3

Group Mean Scores and Dependent Variables

Descriptive Statistics	*Participant groups*	*Mean*	*Standard Deviation*	*N*	*P value*
PROCASE posttest calculated sum score	Control, no video or speaker	8.10	1.969	10	
	Video only	7.80	2.040	46	
	Video and Speaker group	9.50	.862	42	
	Total	8.56	1.811	98	.006**
Self-Efficacy addendum posttest calculated sum score	Control, no video or speaker	15.80	4.050	10	
	Video only	16.02	3.221	46	

	Video and Speaker group	16.62	3.371	42	
	Total	16.26	3.353	98	.376
Self-Efficacy posttest calculated sum score	Control, no video, no speaker	16.40	3.340	10	
	Video only	14.87	3.174	46	
	Video and Speaker group	15.64	3.130	42	
	Total	15.36	3.179	98	.378

Note. **Significant $p<.05$, two-tailed

Hypothesis 2

Hypothesis two, which predicted participants who viewed the prostate cancer educational video and heard the prostate cancer survivor's testimonial would demonstrate higher prostate cancer self-efficacy for informed decision making, was supported by MANCOVA with pretest scores as covariates. The MANCOVA, using Pillai's trace, showed a significant effect of the intervention on posttest scores, (V= .28, $F_{6,182}$= 4.937, p= .000). In addition, separate univariate ANOVAs on the outcome variables revealed significant treatment effects on Self-Efficacy posttest calculated sum score, ($F_{2,95}$=4.683, p=.012). However, separate univariate ANOVAs on the outcome variables revealed non-significant treatment effects on Self-Efficacy Addendum posttest calculated sum score, ($F_{2,95}$=1.833, p=.166). Although, the control group demonstrated the greatest group mean on the self-efficacy posttest calculated sum scores. The group means and standard deviations of the Prostate Cancer Self-Efficacy scale and the Self-Efficacy Addendum posttest are displayed in Table 3.

Research Question

The research question, which explored the participants' understanding and confidence in determining and discussing prostate cancer screening options with an HCP, was assessed using data from the focus group discussions. The three focus groups, with 10 participants in each group (the control, video only, and video and speaker groups), identified three overlapping concerns as displayed in Table 4. In addition, the table shows there were four other overlapping concerns that were shared between at least two of the groups.

Table 4

Concerns Identified in Focus Group Discussions (N=30)

Control Group-no video or speaker) (n=10)	*Video Only Group (n=10)*	*Video and Speaker Group (n=10)*
Unsure or uncomfortable bringing up prostate cancer topic with HCP	Unsure or uncomfortable bringing up prostate cancer topic with HCP	Unsure or uncomfortable bringing up prostate cancer topic with HCP
Expressed concern regarding copay/insurance cost	Expressed concern regarding copay/insurance cost	Expressed concern regarding copay/insurance cost
Concerned about sexual prowess	Concerned about sexual prowess	Concerned about sexual prowess
Fear of death related to prostate cancer		Fear of death related to prostate cancer
Uncomfortable with rectal exam		Uncomfortable with rectal exam
Community needing more specific information/advertising related to prostate cancer screening		Community needing more specific information/advertising related to prostate cancer screening
Blood draw over examination	Blood draw over examination	
	Unfamiliar with what PSA is	
	Lack of trust in doctors	
	Lack of knowledge in recognizing prostate cancer symptoms	
Concerned about AIDS		

Discussion

Sample

The overall sample for this study was well-educated and had annual incomes greater than the average household income from this urban community. The median household income for this community in Wilmington, DE, 19801 is $41,035 for all residents and specifically $28,609 for Blacks or African Americans in 2015 (City-Data.com, 2017) . Approximately 1/3 had a conversation about prostate cancer screening with an HCP within the past 12 months. Much of the recruitment for this intervention was done through other organizations such as a prestigious predominantly Black attended church as well as the alumni organizations of college fraternities. Therefore, this sample may not be representative of the community at large. This could represent a limitation of the study.

These sample characteristics played a factor in setting the pretest scores as covariates in the MANCOVA as this would allow for normalization of the baseline dependent variables (knowledge and self-efficacy). This is supported as there was statistical significance with the intervention on posttest scores. However these results may not be generalizable due to the above average annual income and education level identified in this sample. When pretest scores are used as covariates, MANCOVA is useful in the same ways as ANCOVA. In experimental work, it serves as a noise-reducing device where variance associated with the covariate(s) is removed from error variance; smaller error variance provides a more powerful test of mean differences among groups. Prior differences among groups are accounted for by adjusting dependent variables as if all subjects scored the same on the covariate(s) (Cole, Maxwell, Arvey, & Salas, 1994).

Significant differences among participants who spoke with a health care provider about prostate cancer within past 12 months, those who had prostate cancer screening within past 12 months, and those with family history of prostate cancer were demonstrated across selective sub-groups as listed in Table 2. Income, marital status, and education were impactful among the participants who spoke with a health care provider within the past 12 months. Income was also found to be significant among participants with a family history of prostate cancer while marital status was significant among the participants who had screening within the past 12 months.

Overall, this study was rated highly favorable among participants as 91% reported they would recommend this program to other men. Eighty-three percent said they plan to ask their health care provider about prostate cancer screening and 92% agreed the speaker helped them understand the importance of talking with a health care provider about prostate cancer

Hypotheses

Previous studies have demonstrated AA men respond positively to various educational formats such as video presentations, pamphlets or peer educators (Santos et al., 2014; Sheridan, 2012; Ukoli et al., 2013). While previous research in examining the effectiveness of combining an AA prostate cancer survivor's testimonial with an educational video that addresses prostate cancer knowledge and self-efficacy for informed decision making is limited, the study results support the effectiveness of combining an educational video with a testimonial.

As predicted by the theory that guided this study, results supported the positive effect of the intervention on prostate cancer knowledge and self-efficacy for informed decision-making. Participant groups demonstrated a significant increase in prostate cancer knowledge and self-efficacy for informed decision making following the intervention.

Results, however, must be interpreted with caution due to homogeneity of covariance assumption violated. Of interest, it was noted that the control group who neither watched the educational video or heard the speaker's testimonial also had significant increase in posttest knowledge and self-efficacy scores. While the control focus group did not have a formal intervention, the shared group discussions may have contributed to the significant posttest scores and the concerns identified in the group discussion.

Per Social Cognitive Theory, there are four influences on self-efficacy, including vicarious experience. While this explains the effectiveness of the speaker's testimonial, it is possible that the men in the control group by virtue of being in an environment conducive to learning, listening, and expressing their concerns, were provided increased knowledge and confidence regarding prostate cancer and screening.

Posttests from the participants in the focus groups were collected following the group discussions whereas, the men who were not focus group participants had their posttest collected after the video if they were in the video only group or after the testimonial if they were in the video and speaker group. This could have contributed to the differences seen in the quantitative analyses. While the intent was to avoid having the posttest influence the discussions, future recommendations would include a standardized time for collecting the posttest surveys.

Qualitative Findings

Participants in focus groups identified overarching concerns that were consistent across all three focus groups. Overall, the focus group participants appeared to understand the magnitude of prostate cancer and the importance of screening. They could name a few risk factors and concerns regarding prostate cancer, but shared some myths surrounding how someone contracts prostate cancer. The men expressed concern regarding the effect of diagnosis on sexual performance. They did not express concerns regarding urinary problems associated with prostate cancer, however. They were receptive to listening to each other's thoughts and open to being corrected by other participants. Upon conclusion of the focus groups, participants expressed gratitude for information and said they would follow up with an HCP regarding their prostate cancer screening options.

Bandura's Social Cognitive Theory emphasizes the importance of observing and modeling behaviors, attitudes, and emotional reactions of others. Both the environmental and cognitive factors interact to influence human learning and behavior. The environment, which was a private small group setting, provided an atmosphere where the participants could observe the behavior of others. The group participants were likely learning from each other within a social context.

Cultural influences are also critical. Having an AA male as the group facilitator and another as the scribe were beneficial. However, the facilitator was not local to the community and this may have influenced the means by which the participants communicated. If repeated, it is recommended that both the facilitator and scribe are AA men from the local community as this could impact the comfort level or comradery among the participants. In addition, should the study be repeated, it will be imperative to have clear audio recordings so that more of the participants' expressions can be recorded verbatim.

Both quantitative and qualitative assessments were used to determine participants' knowledge and self-efficacy for prostate screening. Using the two approaches allowed for a more thorough understanding of participants' understanding. Both the quantitative and qualitative results provide insight into participants' knowledge and self-efficacy for prostate screening, but were not necessarily in agreement (see Table 5). The specific reasons for these differences are unclear but it is not unusual to see varying results from quantitative versus qualitative measures. This is a reason to do mixed methods studies as conclusions gleaned from two strands are integrated to provide a fuller understanding of the phenomenon under study (Teddie & Tashakori, 2009).

Table 5

Comparison of Quantitative and Qualitative Results

Concept/Variable	*Quantitative*	*Qualitative*
Knowledge		
Urinary problems associated with prostate cancer	Significant	Non-significant
Loss of sexual function related to prostate cancer	Significant	Significant
Self-efficacy		
Recognition of prostate cancer warning signs	Significant	Significant
Comfortable talking with HCP regarding prostate cancer screening options	Non-significant	Significant
Cost/copay of prostate cancer screening	Non-significant	Significant

While posttests on the PCS were not significant, the qualitative findings suggested the participants were confident in their ability to talk with an HCP regarding their options for prostate screening. As noted, it may be that the focus group itself increased confidence levels. Conversely, quantitative findings indicated participants understood the urinary problems associated with prostate cancer but this was not supported by the qualitative findings. It is possible that, while knowledgeable, this particular issue was of less concern than the loss of sexual function. In addition, the qualitative findings revealed that, for some participants, issues such as lack of trust in the physician and recognizing symptoms of prostate cancer were of concern but not necessarily measured in the quantitative surveys.

Conclusion

While prostate cancer is a significant health problem for men in the United States, it is more prevalent among AA men and contributes to increased mortality. With the changing and possibly confusing landscape regarding routine PSA testing, the ACS (2016) recommends prostate cancer screening should not occur without an informed decision-making process.

Despite some limitations in the study that included a selective sample of educated men who were primarily recruited from college alumni fraternities or by their attendance at a prestigious AA church, the participants who viewed an educational video and heard an AA prostate cancer survivor's testimony significantly increased their prostate cancer knowledge. In addition, the overall small sample size and unequal group sizes could be a limitation of study as results can not be generalized to the population. If given the opportunity to repeat the study, more time would be given to recruit participants so that the sample is more representative of the community, that enough participants could be recruited so the intervention is completed in one setting at the same location, and equal group sizes would be obtained as small groups have more variance.

Perhaps, the most significant study limitation is the inaudible recordings from the focus group discussions. Having limited verbatim comments left the PI to rely heavily on the scribe's notes leaving room for error or misinterpretation. If given the opportunity to repeat the study, a complete sound check fully testing all equipment at the selected venue would be implemented. Also, careful consideration would be made when considering the focus group facilitator to include a local AA man rather than a Nigerian-born man as there may be some cultural differences that may be misinterpreted.

Overall, this study was rated highly favorable among participants as more than 90% agreed they would recommend this program to other men and that the speaker helped them understand the importance of talking with a health care provider about prostate cancer screening. Results of this mixed methods study support the effectiveness of a targeted, culturally relevant prostate cancer educational screening intervention that increased prostate cancer knowledge and self-efficacy for informed decision making among AA men.

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Chapter Four. Summary and Conclusion

This program of research commenced with an interest in health disparities related to cancer education and prevention in African Americans as well as low socioeconomic and vulnerable populations. Early research led to identification of barriers to cancer education and access to treatment for this population. Communication, cultural influences, and health literacy were reoccurring themes identified. Defining health literacy and understanding the significance on cancer education, prevention and treatment led to a concept analysis and the first manuscript, *Health Literacy Among African Americans: An Oncology Focus.* The definition of health literacy remains ambiguous but it influences African American health consumers' understanding of disease prevention and management, self-efficacy, perceived susceptibility, adherence to medical protocols, informed consent, and medication administration (Weekes, 2012).

Health literacy is a critical issue as low health literacy is associated with worse health outcomes especially in vulnerable populations like African Americans and low socioeconomic status health consumers. Awareness and attention to health literacy needs of all patients will promote the nursing goal of optimizing health care delivery. Clarifying the concept of health literacy is an important primary step towards improving patient outcomes.

Findings from the initial health literacy analysis led to examining educational interventions that were targeted with cultural sensitivity to African Americans and reported in Chapter Three, titled *African American Men's Prostate Cancer Knowledge and Self-Efficacy for Informed Decision Making: A Mixed Methods Study.* This report of original research evaluated the effectiveness of an educational intervention on African American's prostate cancer knowledge and self-efficacy for informed decision-making. Combining a prostate cancer survivor's testimonial with and educational video significantly increased knowledge and self-efficacy among African American men. Study findings suggest while an educational video may be effective in increasing prostate cancer knowledge, combining more targeted interventions like the testimony of a person with whom the participants can identify, may be more impactful among African American men. Future studies should examine the effectiveness of more combination educational interventions as well as educational interventions using community or peer survivors. Participants in focus groups identified overarching concerns that were consistent across all three focus groups. There were some aspects about cancer knowledge and self-efficacy for informed decision making that were found to be significant quantitatively but were not reflected in the qualitative findings. The reverse was also true, with participants identifying issues not reflected in the quantitative results.

Findings from this study have implications for nurses to apply targeted educational interventions that are culturally appropriate and meets the needs of the intended audience. Researchers have noted the need for development and utilization of targeted educational interventions to meet the diverse health care needs of people in this country (Saunders et al., 2013; Song et al., 2012; Vikaykumar et al., 2013). Developing interventions aimed at enhancing patient's cancer-related self-efficacy along with knowledge in cancer treatment and care may facilitate better well-being, patient involvement, and behavior (Nielsen et al., 2013). According to Bandura's SCT, both environmental and cognitive factors interact to influence human learning and behavior that occurs within a social context. Behavior can influence both the environment and the person as all three influence each other.

There has been evidence of applying Bandura's theory of self-efficacy in oncology suggesting relationships between self-efficacy and cancer prevention and self-efficacy and adaptation to cancer (Boehm et al., 1995; Lev, 1997; Zhang et al., 2014). African American men continue to face challenges with prostate cancer screening decision-making and also in the way they experience the health care system. Low levels of knowledge are associated with low self-efficacy and low rates of cancer screening prevention among disadvantaged populations (Ford et al., 2011). Boehm et al. (1995) state that when initiating regular screening behaviors, "challenges are increased for individuals who must deal with additional issues of being AA, male and elderly, and other issues such as lack of health care and racial insensitivity in the health care system" (p. 162). Therefore, there is a need to examine the effectiveness of targeted prostate cancer educational interventions to increase prostate cancer knowledge, self-efficacy for informed decision-making related to screening options.

Exploring strategies to improve communication from the perspective of AA men will help better understand the cancer beliefs in this population (Song et al., 2012). It is important for nurses to consider the various levels of education and background of patients when developing strategies to uncover barriers to communication as some individuals are highly educated but still do not recognize the importance of some preventative or medical treatment. The modeling of a prostate cancer survivor (peer educator) sharing his testimonial to men who could identify with him was beneficial for the participants in this study. Vikaykumar et al. (2013) found cancer survivor educators were rated more highly than health educators and cancer survivor educators were found to be more trustworthy among 63 AA men who attended a prostate cancer screening session conducted by a cancer survivor educator and a health care educator. Song et al. (2012), in their qualitative interviews of 28 AA cancer patients, found it is critically important to develop tailored educational interventions for AA men given the state of disparities in incidence, mortality, and survival rates.

Implications for nursing practice is multidimensional as diversity expands beyond race, gender, education, sexual preference, or political views. It includes experiences, perspectives, as well as beliefs. Future studies will need to focus on ways that acknowledge the diverse population of people in this country while increasing knowledge, correcting myths, and perceived risk for participants in a variety of settings. Results of this original research will help guide future educational interventions geared towards specific groups (i.e., Hispanics, Asians, women, etc.) in meeting the needs specific for them. Future research should focus on increased awareness of health literacy among health care providers and more effective communication strategies that are culturally appropriate.

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Appendix A: Institutional Review Board Approval

THE UNIVERSITY OF TEXAS AT TYLER
3900 University Blvd. • Tyler, TX 75799 • 903.565.5774 • FAX: 903.565.5858

Office of Research and
Technology Transfer

Institutional Review Board

December 16, 2015

Dear Ms. Dendy,

Your request to conduct the study: *An Educational Intervention on African American Men's Prostate Cancer Knowledge and Self-Efficacy for Informed Decision-Making*, IRB #F2015-37 has been approved by The University of Texas at Tyler Institutional Review Board under expedited review. This approval includes the written informed consents that are attached to this letter, and your assurance of participant knowledge of the following prior to study participation: this is a research study; participation is completely voluntary with no obligations to continue participating, and with no adverse consequences for non-participation; and assurance of confidentiality of their data.

In addition, please ensure that any research assistants are knowledgeable about research ethics and confidentiality, and any co-investigators have completed human protection training within the past three years, and have forwarded their certificates to the IRB office (G. Duke).

Please review the UT Tyler IRB Principal Investigator Responsibilities, and acknowledge your understanding of these responsibilities and the following through return of this email to the IRB Chair within one week after receipt of this approval letter:

- This approval is for one year, as of the date of the approval letter
- **The Progress Report form must be completed for projects extending past one year.** Your protocol will automatically expire on the one year anniversary of this letter if a Progress Report is not submitted, per HHS Regulations **prior** to that date (45 CFR 46.108(b) and 109(e): http://www.hhs.gov/ohrp/policy/contrev0107.html
- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity

EQUAL OPPORTUNITY EMPLOYER

- **Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others**
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.

Best of luck in your research, and do not hesitate to contact me if you need any further assistance.

Sincerely,

Gloria Duke, PhD, RN

Gloria Duke, PhD, RN
Chair, UT Tyler IRB

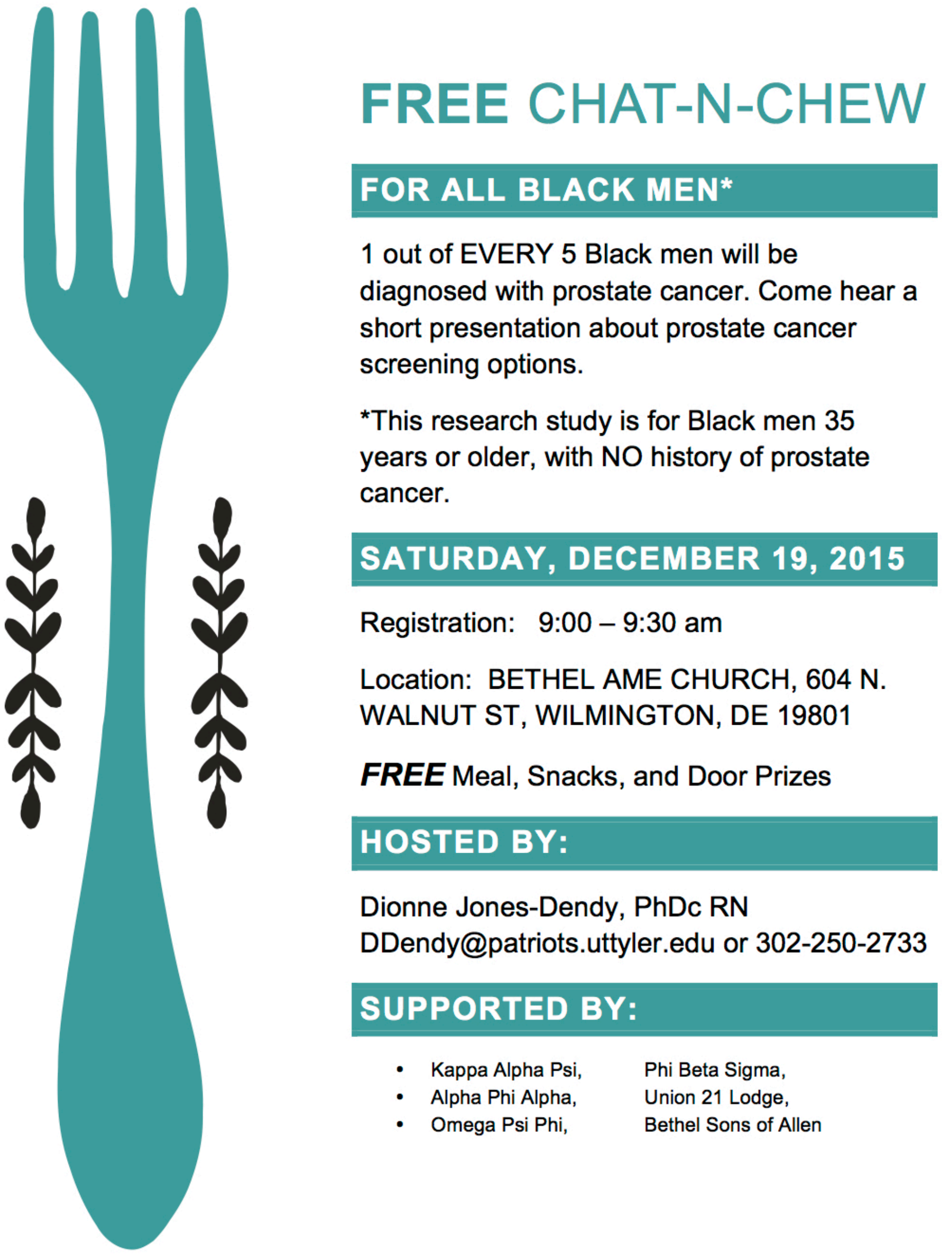
Appendix B: Social Cognitive Theory Principles

Primary Principles of the Social Cognitive theory

1. The observer will imitate the model's behavior if the model possesses characteristics (such as talent, intelligence, power, good looks, or popularity) that the observer finds desirable.
2. Individuals are more likely to adopt a modeled behavior if the model is similar to the observer, has admired status, and the behavior has functional value.
3. The observer will react to the way the model is treated and then imitate the model's behavior. If the model is rewarded then the observer is more likely to perform the behavior. If the model is punished then the observer is less likely to repeat the behavior.
4. There is a difference between an observer's "acquiring" a behavior and "performing" a behavior. By observing, the observer can acquire the behavior and not perform the behavior. The observer may then choose to perform the behavior later on if the situation seems right.
5. Coding modeled behavior into labels, words or images results in better retention than just observing.
6. Learning by observation involves four different processes: attention, retention, motor production, and motivation/reinforcement.
7. Attention and retention account for learning a model's behavior. Whereas, motor production and motivation control the performance of the behavior.
8. Human development reflects the complex interaction of the person, the person's behavior, and the environment. A lot of what a person knows comes from the

environmental resources such as television, parents, and books. The environment also affects behavior: what a person observes can powerfully influence what he or she does. But a person's behavior can also contribute to his or her environment.

Appendix C: Recruitment Flyer



FREE CHAT-N-CHEW

FOR ALL BLACK MEN*

1 out of EVERY 5 Black men will be diagnosed with prostate cancer. Come hear a short presentation about prostate cancer screening options.

*This research study is for Black men 35 years or older, with NO history of prostate cancer.

SATURDAY, DECEMBER 19, 2015

Registration: 9:00 – 9:30 am

Location: BETHEL AME CHURCH, 604 N. WALNUT ST, WILMINGTON, DE 19801

FREE Meal, Snacks, and Door Prizes

HOSTED BY:

Dionne Jones-Dendy, PhDc RN
DDendy@patriots.uttyler.edu or 302-250-2733

SUPPORTED BY:

- Kappa Alpha Psi,
- Alpha Phi Alpha,
- Omega Psi Phi,

Phi Beta Sigma,
Union 21 Lodge,
Bethel Sons of Allen

Appendix D: Informed Consent

THE UNIVERSITY OF TEXAS AT TYLER

Informed Consent to Participate in Research

Institutional Review Board # F2015-37
Approval Date:

1. **Project Title**: An Educational Intervention on African American Men's Prostate Cancer Knowledge and Self-Efficacy for Informed Decision-Making

2. **Principal Investigator:** Dionne Jones-Dendy

3. **Participant's Name:**

To the Participant:

You are being asked to take part in this study at The University of Texas at Tyler (UT Tyler). This permission form explains:

- Why this research study is being done.
- What you will be doing if you take part in the study.
- Any risks and benefits you can expect if you take part in this study.

After talking with the person who asks you to take part in the study, you should be able to:

- Understand what the study is about.

- Choose to take part in this study because you understand what will happen

4. Description of Project

The purpose of this study is to see if one type of education is better than another in

teaching African-American men about prostate cancer screening.

5. Research Procedures

If you agree to be in this study, we will ask you to do the following things:

1. Before the session begins, complete paperwork asking questions about you (for example: age, work). Other questions will ask about prostate cancer screening, risks of disease, and your feelings towards about prostate cancer screening.
2. Possibly watch a video and maybe listen to a cancer survivor's presentation on prostate cancer.
3. Discuss the video and presentation (if applicable) with the group. This session will be audio-recorded.

4. Complete additional paperwork asking questions about prostate cancer screening before leaving.

6. Side Effects/Risks

You may become slightly distressed when learning about prostate cancer and hearing someone speak about their experience with the disease, though this is not expected to be a common problem. Should you become distressed, you can choose to stop participating. If needed, the researcher can refer you for help.

7. Potential Benefits

As a participant, you may learn important information that could help save your life in the future. You will also help researchers, like nurses and doctors, design educational programs specifically for African American men.

Understanding of Participants

8. I have been given a chance to ask any questions about this research study. The researcher has answered my questions.

9. If I sign this consent form I know it means that:

- I am taking part in this study because I want to. I chose to take part in this study after having been told about the study and how it will affect me.
- I know that I am free to not be in this study. If I choose to not take part in the study, then nothing will happen to me as a result of my choice.
- I know that I have been told that if I choose to be in the study, then I can stop at any time. I know that if I do stop being a part of the study, then nothing will happen to me.
- I will be told about any new information that may affect my wanting to continue to be part of this study.
- The study may be changed or stopped at any time by the researcher or by The University of Texas at Tyler.
- The researcher will get my written permission for any changes that may affect me.

10. I have been promised that that my name will not be in any reports about this study unless I give my permission.

11. I also understand that any information collected during this study may be shared as long as no identifying information such as my name, address, or other contact information is provided. This information can include health information. Information may be shared with:

- Organization giving money to be able to conduct this study
- Other researchers interested in putting together your information with information from other studies
- Information shared through presentations or publications

12. I understand The UT Tyler Institutional Review Board (the group that makes sure that research is done correctly and that procedures are in place to protect the safety of research participants) may look at the research documents. These documents may have information that identifies me on them. This is a part of their monitoring procedure. I also understand that my personal information will not be shared with anyone.

13. I have been told about any possible risks that can happen with my taking part in this research project.

14. I also understand that I will not be given money for any patents or discoveries that may result from my taking part in this research.

15. If I have any questions concerning my participation in this project, I will contact the principal researcher: Dionne Jones-Dendy at 302-250-2733 or email DDendy@patriots.uttyler.edu.

16. If I have any questions concerning my rights as a research subject, I will contact Dr. Gloria Duke, Chair of the IRB, at (903) 566-7023, gduke@uttyler.edu, or the University's Office of Sponsored Research:

The University of Texas at Tyler
c/o Office of Sponsored Research
3900 University Blvd
Tyler, TX 75799

I understand that I may contact Dr. Duke with questions about research-related injuries.

17. **<u>CONSENT/PERMISSION FOR PARTICIPATION IN THIS RESEARCH STUDY</u>**

I have read and understood what has been explained to me. I give my permission to take part in this study as it is explained to me. I give the study researcher permission to register me in this study. I have received a signed copy of this consent form.

Signature of Participant Date

Signature of Person Responsible (e.g., legal guardian)

Relationship to Participant

Witness to Signature

18. I have discussed this project with the participant, using language that is understandable and appropriate. I believe that I have fully informed this participant of the nature of this study and its possible benefits and risks. I believe the participant understood this explanation.

Researcher/Principal Investigator Date

Appendix E: Demographic Data Sheet

Directions: Complete the form by writing your age on the line. Answer each question by circling the choice that best applies to you.

Table 6. Demographic Questionnaire			
AGE (years) ______________________			
Household Income, per year	Less than $25,000	Between $25,000-75,000	Higher than $75,000
Marital Status	Married	Not Married	Not Married but living with partner
Employment Status	Full-time	Part-time	Not working
Education	Did not complete High School	Completed High School or GED	Completed courses beyond High School
Health Insurance	Private (for example, Blue Cross, Aetna, United)	Government (Medicare, Medicaid, Disability)	No Health Insurance
Talked with health care provider about prostate cancer screening (past 12 months)	Yes	No	
Had prostate cancer screening (past 12 months)	Yes	No	
Family history of prostate cancer?	Yes	No	

Appendix F: PROCASE Knowledge Index Tool

PROCASE Knowledge Index tool

Directions: Place a check in the box that best represents how you feel regarding that statement.

Most men diagnosed as having Prostate Cancer die of something else	TRUE	FALSE
Men are more likely to die because of Prostate Cancer than because of heart disease	TRUE	FALSE
Prostate Cancer is the MOST COMMON cause of problems with urination	TRUE	FALSE
Prostate Cancer NEVER causes problems with urination	TRUE	FALSE
Prostate Cancer is one of the LEAST common cancers among men	TRUE	FALSE
The PSA (prostate specific antigen) test will pick up ALL prostate cancers	TRUE	FALSE
A prostate biopsy can tell you with more certainty whether you have prostate cancer than a PSA test can	TRUE	FALSE
If you have an ABNORMAL PSA test result, your doctor may recommend that you have a prostate biopsy	TRUE	FALSE
Loss of sexual function is a common side effect of prostate cancer treatments	TRUE	FALSE
Problems with urination are common side effects of prostate cancer treatments	TRUE	FALSE

Appendix G: Prostate Cancer Self-Efficacy Screening Scale

Directions: Place a check in the box that best represents how you feel regarding that statement.

	Not at All	Not Likely	Likely	Very Likely	Extremely Likely
How sure are you that you can:					
(a) have a PSA blood test to check your prostate for cancer					
(b) have a digital rectal exam (DRE) to check your prostate for cancer					
(c) have an examination every year to check your prostate for cancer					
(d) recognize the warning signs of prostate cancer?					

Appendix H: Self-Efficacy Addendum

Directions: Place a check in the box that best represents how your confidence regarding that statement.

	Not Confident at All	Not Very Confident	Somewhat Confident	Quite Confident	Very Confident
I can make an appointment with my health care provider within the next six months					
I can talk with my health care provider about prostate screening options					
I can afford to have prostate screening done					
I can travel as needed to receive prostate cancer screening					

Appendix I: Program Evaluation

Program Evaluation

Directions: Put a check mark in the box that best represents your feelings for that statement.

	Strongly disagree	Disagree	Undecided	Agree	Strongly Agree	Does not apply to me
The program increased my awareness of prostate cancer						
My knowledge of the risks of prostate cancer increased						
The video helped me understand the importance of talking with my health care provider about prostate cancer treatment options						
The speaker helped me understand the importance of talking with health care provider about prostate						
The focus group discussion among the men was helpful in my understanding						
I plan to ask my health care provider about prostate cancer screening						
I would recommend this program to other men						

Appendix J: Permission to Use Educational Video

From: Permission Requests [permissionrequest@cancer.org]
Sent: Tuesday, November 24, 2015 11:38 AM
To: Dionne Dendy
Cc: Permission Requests
Subject: PER.15.432 - Use of Prostate Cancer: Informed Decision Making for Patients video

Dear Ms. Dendy,
Please provide more detailed information of how the video will be broadcast or distributed, for instance, burned to a disc, digitized, streamed directly from website, etc. If you are streaming directly from the website, written permission is not needed. Thank you.

****

Danielle Musgrove, Analyst, Compliance
t) 202.661.5768 f) 202.661.5750

TaSonja Hibbler, Paralegal
t) 404.329.7638 f) 404.417.5808

****

Permission Requests:
American Cancer Society, Inc.
250 Williams Street
Atlanta, GA 30303

Appendix K: Permission to use PROCASE

PERMISSION TO USE AN EXISTING SURVEY

Re: permission to use PROCASE Knowledge Index tool
David Radosevich PhD [davidmr@umn.edu]
You forwarded this message on 11/9/2015 1:59 PM.
Sent: Monday, November 9, 2015 1:15 PM
To: Dionne Dendy; David Radosevich [davidmr@umn.edu]

Dionne,

Thanks for your inquiry. You have my permission to use the PROCASE Knowledge Index.

I appreciate any feedback you have regarding the use of the instrument. It is beneficial to my self and others doing work in this area.

Best of luck and success in completing your dissertation.

David

On Mon, Nov 9, 2015 at 11:34 AM, Dionne Dendy <ddendy@patriots.uttyler.edu> wrote:
Permission to Use an existing survey

November 7, 2015

David M. Radosevich
Department of Surgery
B-139 PWB
516 Delaware St SE
Minneapolis, MN 55455

Dear Mr. David M. Radosevich:

I am a doctoral student from the University of Texas at Tyler writing my dissertation tentatively titled African American Men Prostate Cancer Knowledge and Self-Efficacy: A Mixed Methods Study under the direction of my dissertation committee chaired by Dr. Barbara Haas.

I would like your permission to reproduce to use Prostate Cancer Screening Education Knowledge Index in my research study. I would like to use and print your survey under the following conditions:

¥ I will use this survey only for my research study and will not sell or use it with any compensated activities.
¥ I will include the copyright statement on all copies of the instrument.

¥ I will send my research study and one copy of reports, articles, and the like that make use of these survey data promptly to your attention.

If these are acceptable terms and conditions, please indicate so by signing one copy of this letter and returning it to me either through postal mail or e-mail with your signature:

228 Red Tailed Hawk Lane
Middletown, DE 19709

Sincerely,
Dionne Jones-Dendy
Doctoral Candidate

Appendix L: Prostate Cancer Screening Self-Efficacy Scale

RE: Permission to use tool
sboehm sboehm [sboehm@umich.edu]
You replied on 11/23/2015 10:20 PM.
Sent: Monday, November 23, 2015 4:04 PM
To: Dionne Dendy

Dionne, You have my permission and best wishes for your successful research.
Susan Boehm

-----Original Message-----
From: Dionne Dendy [mailto:ddendy@patriots.uttyler.edu]
Sent: Monday, November 23, 2015 8:23 AM
To: Sboehm@umich.edu
Cc: Dionne Dendy <ddendy@patriots.uttyler.edu>; djdendy@aol.com
Subject: RE: Permission to use tool

Hello Dr Boehm,

I am a doctoral student at the University of Texas at Tyler requesting permission to use the Prostate Cancer Screening Self-Efficacy Scale during my research intervention next month. Please see details of request below.

Thanks in advance,
Dionne Jones-Dendy
302-250-2733

From: Dionne Dendy
Sent: Tuesday, November 10, 2015 8:10 PM
To: Sboehm@umich.edu
Subject: FW: Permission to use tool

Appendix M: Focus Group Discussion Guide

1. Please describe prostate cancer for me.
    a. Who may or may not be at risk?
    b. Can you describe some of the warning signs of prostate cancer? If you had one or more of these signs, what would you do?
    c. What about screening options? Which screening test (blood draw or rectal exam) would you consider? Why?
    d. What have you heard about prostate cancer? In Black men? And sexual activity?
2. Tell me about your comfort in talking to your health care provider about prostate screening options.
    a. How confident are you in initiating that discussion?
    b. What would help you to have that conversation with a health care provider?
    c. What would be a reason you would not talk to a health care provider about prostate cancer? Prostate cancer screening?
    d. Where would you go to talk to a health care provider about prostate cancer?
    e. How would you travel to talk to a health care provider about prostate cancer?
    f. How would you pay for talking to a health care provider about prostate cancer prevention?

BIOGRAPHICAL SKETCH

NAME: Dionne J Jones-Dendy

eRA COMMONS USER NAME (credential, e.g., agency login):

POSITION TITLE: Doctoral Candidate, The University of Texas at Tyler; Medical Science Liaison at Bayer Healthcare

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Completion Date MM/YYYY	FIELD OF STUDY
The University of Delaware, Newark, DE	BSN	05/1992	Nursing
Pennsylvania State University, University Park, PA	MMgt.	06/1997	Health Care Administration
The University of Pennsylvania, Philadelphia, PA	MSN	08/2004	Nursing
The University of Texas at Tyler, Tyler, TX	PhD	05/2017	Nursing

A. Personal Statement

B. Positions and Honors

2015-Present	Medical Science Liaison, Bayer Healthcare
2008-2015	Senior Oncology Clinical Liaison, Genentech BioOncology
2004-2008	Oncology Nurse Practitioner, Medical Oncology Hematology Consultants

1999-2002	Product Line Manager, Philadelphia Veterans Affairs Medical Center

C. Contributions to Science/Professional Memberships

American Society of Clinical Oncologist

Chi Eta Phi Professional Nursing Sorority

Oncology Nursing Society

Phi Kappa Phi Honor Society

Sigma Theta Tau International Nursing Honor Society

D. Additional Information: Research Support and/or Scholastic Performance