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Prostate Cancer and Afro-Caribbean Men: Experiences, Perceptions, and Beliefs

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Walden University

College of Health Sciences

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Harold Taitt

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Abstract

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by

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MBA, Carlson School of Management, University of Minnesota, 1990

Graduate Certificate, Health Services Management, DeVry University, 2010

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Health Services

Walden University

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Abstract

Despite the high incidence of prostate cancer (PC) amongst men of African descent, there is a paucity of qualitative data that explores how Afro-Caribbean men perceive their risk, susceptibility to, and management of this disease. This phenomenological study sought to explore and analyze beliefs about PC in a sample of Afro-Caribbean men who reside in the United States (U.S.). The research questions considered the perceptions, beliefs, and lived experiences of participants. The conceptual framework is a synthesis of the health belief model (HBM) and the theory of reasoned action (TRA), primarily because the TRA allows for a culturally-based relevance and perspective that is lacking in the HBM. Data were collected using in-depth interviews from a purposive sample of 13 U.S. participants from 7 Caribbean territories, who provided detailed descriptions of their perceptions. Data management and inductive, iterative analysis were facilitated through the use of the NVivo 10 software program. This study found that participants had a low level of awareness and education about PC, but they also believed that if PC were caught early, they have a good chance of a long life. There was no indication that culture played a significant role in their attitudes, beliefs, and perceptions of the disease. Education about PC should be targeted to this population as well as their significant others. In addition, qualitative research is needed to compare perspectives of Afro-Caribbean, African American, and African men who all reside in the United States. This study may contribute to positive social change by providing practical strategies that may increase screening and early diagnosis among Afro-Caribbean men, thereby reducing the mortality from this disease.

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Dedication

To my dad Harold Taitt Senior, who is 91 and has been an inspiration to persevere and achieve all that I can. His love of God, his concern for family, and the stories he shares about his travels and experiences during World War II have never ceased to intrigue and fascinate me. Despite having to leave school at the tender age of 12, he obtained his Doctor of Philosophy in Religion later in life and became an ordained minister. My dad also has a history of prostate issues and that was a partial reason why I chose a topic relating to prostate cancer. I also dedicate this accomplishment to my daughter Nyoka Taitt, whose confidence and desire to succeed will take her wherever she chooses to go in this life.

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Chapter 1: Introduction to the Study

Prostate cancer is the most frequently diagnosed cancer in the United States (U.S.) and accounts for approximately 33% of all cancer cases among men (American Cancer Society, 2013). Hsing, Tsao, and Devesa (2000) observed that there are clear associations between prostate cancer and race, and those of African descent, particularly African-Americans, have been found to have the highest incidence of prostate cancer in the world (Hsing et al., 2000). In many developed countries, prostate cancer is one of the most significant and frequently occurring cancers and is the second leading cause of death amongst men in the United States after cancers of the lung and bronchus (ACS, 2013; Siegel, Naishadham, & Jemal, 2013). In developing countries, the data are not as clear, and several researchers have presumed that prostate cancer is less common in those countries.

According to Zeigler-Johnson et al. (2008), prostate cancer incidence and mortality rates have been reported to be low in native Africans and men of African descent who are not African-Americans. However, researchers such as Glover et al. (1998), Ben-Shlomo et al. (2008), and Hennis, Wu, Nemesure, and Leske (2013) have reported that particularly high prostate cancer incidence rates have been found in native Afro-Caribbean men and Black men residing in the United Kingdom (U.K.).

Worldwide and U.S. data on the incidence and mortality rates for prostate cancer vary depending on the source. For example, Siegel et al. (2013) reported that a total of 238,590 new prostate cancer cases were estimated to occur in the United States in 2013, of which 29,720 men were expected to die. In addition, Siegel et al. argued that the

projected death rate from prostate cancer relative to all cancers in men will be 9.7%, second only to projected deaths from lung/bronchus cancer at 28.4%. Approximately 12.5% of all men diagnosed with prostate cancer in the United States were estimated to die from the disease in 2013 (ACS, 2013; Siegel et al., 2013).

Despite the high incidence of prostate cancer amongst men of African descent as reported by Glover et al. (1998), Ben-Shlomo et al. (2008), and Hennis et al. (2013), only a few studies by researchers such as Rajbabu et al. (2007) and Nanton and Dale (2011) have focused on the experiences, perspectives, and beliefs of native Afro-Caribbean men and Black men residing in the United Kingdom or the United States. Given the lack of available data on perceptions and beliefs of Afro-Caribbean men relative to prostate cancer, this study is necessary as I seek to provide pertinent and current information from that group of men.

The findings from this study may have social implications because they show that educational and promotional efforts should be aimed at increasing knowledge of risk and susceptibility to the disease among Afro-Caribbean men. These findings also demonstrate that there is a need for encouraging early diagnosis and intervention among Afro-Caribbean men aimed at reducing the morbidity and mortality from the disease.

In Chapter 1 of this study, I address the problem of prostate cancer as it relates to the study topic and the research questions that need to be answered. I also discuss the purpose of this qualitative study and the relationships between two models that were synthesized into a conceptual framework to help explain the key concepts for this study. In addition, I outline the assumptions, scope, delimitations, limitations, and the

significance of this study as well as a synopsis on the importance and implications of this research relative to social change. Finally, I conclude with a summary of the main points presented in this chapter, and provide a transition statement that leads into Chapter 2.

Background

The data on prostate cancer in Afro-Caribbean men residing in the United States are sparse. There are very little data in the literature on how these men view prostate cancer, their susceptibility to the disease, and their attempts or motivation to take early detection measures to minimize their mortality from the disease. A systematic review of the literature demonstrates that one of the few qualitative study that focused on Afro-Caribbean men in the United States only captured the perspectives of Jamaicans and Haitians (Kleier, 2004). One of the difficulties in categorizing men residing in the Caribbean or of Caribbean ancestry as a single group is the fact that the Caribbean is comprised of more than 40 different territories with different cultures, languages, and histories. It is problematic to assert that a sample of men from only a few Caribbean countries may be representative of the perspectives of Caribbean men.

History of the Caribbean Region

The Caribbean region consists of the Bahamas, the Greater Antilles, which are made up of the islands of Jamaica, Cuba, Hispaniola, and Puerto Rico, Guyana, the Lesser Antilles that comprise the chain of islands north and north east of the Venezuelan coast, and the islands of Barbados, Trinidad, and Tobago. The inhabitants of the majority of these islands are descendants of African laborers, Caucasian and mixed-race indentured servants, and migrants from the Middle East, India, and China (Benn-Torres

et al., 2008). Consequently, the majority of inhabitants of the Caribbean region share a common ancestry with African-Americans whose ancestors also originated from West Africa.

Afro-Caribbean men, African American Men and Prostate Cancer

Given the common ancestry and other similarities between African-Americans and Afro-Caribbean men, one might expect them to have similar prostate cancer incidence rates. However, several studies that I discuss later in this study not only document differences in incidence rates between African-American and Afro-Caribbean men but also show differences in rates for the same countries from one study to the next. Consequently, there is uncertainty and ongoing debate about what the true incidence rates are for Afro-Caribbean men. This study was designed to investigate the views and experiences of Afro-Caribbean men relative to prostate cancer, with the possibility that those views may be different from those of African-American men.

Based on the 2010 United States Census Bureau Report of the foreign-born population in the United States, the total number of people from the Caribbean region who are residing in the United States is approximately 3,731,000, representing 9.3% of the foreign-born population (Grieco et al., 2012). The United States Census Bureau uses “foreign-born” to represent anyone who is not a US citizen at birth and includes naturalized US citizens, legal permanent residents, temporary migrants, humanitarian migrants, and unauthorized migrants. Grieco et al. (2012) noted that almost 60% of foreign-born residents from the Caribbean are over 45 years of age of which 46.5% are men. Forty nine percent of Caribbean immigrants in the United States identified

themselves as “Black” or of African descent based on 2008-2009 data (Thomas, 2012).

If one uses the 2008-2009 statistics on the percentage of Black men from the Caribbean, there are more than 509,215 Afro-Caribbean men over 45 years of age currently residing in the United States who are at risk for prostate cancer.

The etiology of prostate cancer is still unclear, and there have been many theories on why a difference exists in the incidence, morbidity, and mortality based on race and ethnicity as evidenced in Caucasian men, men of African descent, Asians, Native Americans, and other races. According to Meehan (2002), and Hsing and Devesa (2001), the only established risk factors for prostate cancer are increasing age, family history, and ethnic origin. However, Pienta and Esper (1993) suggested that the involvement of endogenous hormones may help explain why it is difficult to determine risk factors for this disease. There have been theories for varying levels of increased risk associated with dietary levels of fat intake, vitamin D, bone mineral density, vasectomy, cadmium exposure, smoking, and other contributors that are expanded on in Chapter 2.

African-American males are more likely to be diagnosed with and die from prostate cancer than Caucasian males and males from all other races in the United States (Siegel et al., 2013). Siegel et al. (2013) continued that the ACS estimated the incidence of prostate cancer (per 100,000) amongst African-American males between the years 2005 and 2009 was 228.7, versus 141.0 in Caucasian males. The death rate from prostate cancer (per 100,000) in African-American males was 53.1 versus 21.7 in Caucasian males (Siegel et al., 2013).

Several studies have focused on prostate cancer in African-American males, but little is known about the incidence, experiences, perceptions, attitudes, and perspectives of Afro-Caribbean men residing in the United States relative to this disease. Consedine, Magai, Cohen, and Gillespie (2002) asserted that this is primarily because studies often combine different ethnicities such as Caribbean, African, and African-American men under the single racial category of African-American or Black.

Despite the larger number of studies that look at prostate cancer in the African-American population, one cannot presume that Afro-Caribbean men have the same or similar perceptions and attitudes to the disease simply because they may share the same genetic characteristics and skin color. For example, US immigrants experience higher mortality rates for many cancers due to a variety of sociocultural factors, including lack of cancer education and awareness, lack of access to preventative and screening services, language, and cultural beliefs. Although it has been consistently reported that African-American men have the highest rate of prostate cancer in the world, the findings of one study of Jamaicans by Glover et al. (1998) suggested that Caribbean men may have an even higher incidence of the disease.

Given that few researchers have looked at the experiences and perspectives towards prostate cancer of Afro-Caribbean men residing in the United States, additional research is needed to provide insight into what is known about prostate cancer and the attitudes of this ethnic group towards the disease. The data on the higher incidence of prostate cancer and associated mortality among men of African descent seem to point to the need for increased awareness and early diagnosis of the disease (Kleier, 2004). That

awareness and the motivation to seek testing and early diagnosis may be associated with the beliefs, experiences, and perceptions of ethnic groups such as Afro-Caribbean men.

This study was designed to explore the experiences, perceptions, and beliefs of Afro-Caribbean men in an attempt to determine if those and other factors have an effect on whether they choose to seek information, early diagnosis, and treatment for prostate cancer.

The findings from this research add to the existing body of knowledge on prostate cancer and Afro-Caribbean men residing in the United States. The findings from this study also provide direction on whether prostate cancer education, outreach efforts, and methods tailored to African-American men are effective in raising the awareness of prostate cancer within the Afro-Caribbean community in the United States of America.

Problem Statement

Researchers of prostate cancer in Afro-Caribbean men on the islands of Jamaica, Martinique, and Guadeloupe have found the prostate cancer incidence to be amongst the highest in the world (Belpomme & Irigaray, 2011; Glover et al., 1998; Mallick et al., 2005). Based on 2008-2009 statistics, there are more than 509,215 Afro-Caribbean men over the age of 45 in the United States (Thomas, 2012). These men may not only be at higher risk and have different perspectives of prostate cancer than African-Americans but may also be likely to have the disease progress to later stages that may be terminal as a consequence of lack of awareness, failure to benefit from early diagnosis through screening, and the option of early treatment modalities.

Experiences, beliefs, and perceptions of prostate cancer may be directly related to whether or not Afro-Caribbean men seek information, education, preventative screening leading to early diagnosis, and treatment for the disease. Determining the effect of those factors may be important in reducing the morbidity and mortality associated with the high incidence of prostate cancer in this ethnic group.

In order to understand the complexities of how Afro-Caribbean men in the United States perceive prostate cancer, it was necessary to conduct a qualitative phenomenological study that represents a larger number of Caribbean countries to determine what their perceptions, beliefs, and experiences are, and how they may affect education, prevention, testing, and possible treatment within the Afro-Caribbean communities.

Phenomenology is concerned with the study of experiences from the perspective of the individual (Moustakas, 1994). Those experiences are based in a paradigm of personal knowledge and subjectivity and the method emphasizes the importance of personal perspective and interpretation (Byrne, 2001). According to Waters (as cited by Bryne, 2001), phenomenologists believe that knowledge and understanding cannot be quantified or reduced to numbers or statistics. Bryne (2001) also argued that phenomenologists believe that truth and understanding of life can emerge from people's life experiences. Phenomenological methods can be very effective in bringing experiences and perceptions to the fore from the perspective of the individual (Bryne, 2001).

Nanton and Dale (2011) noted that Afro-Caribbean men are poorly represented in the cancer research literature in the United Kingdom. To date, there have been few qualitative studies of prostate cancer and Afro-Caribbean men in the United States, and of those studies, most have involved participants from only two or three Caribbean countries (Kleier, 2004; Pedersen, Armes, & Rearn, 2012). Kleier (2003, 2004) argued that based on her review of the literature on prostate cancer in Black men of Afro-Caribbean descent, there is a general lack of knowledge of this disease.

Purpose of the Study

The purpose of this qualitative, phenomenological study was to explore and analyze beliefs about prostate cancer in a sample of Afro-Caribbean men between the ages of 40 and 75 years old who reside in the United States. Health beliefs are important because health behavior may be influenced by what a person thinks or believes about health, and those beliefs may also strongly affect how they utilize health care services (Champion & Skinner, 2008). According to Moustakas (1994), perception is regarded as the primary source of knowledge, and it opens a window unto things.

The aim of the phenomenological approach is to determine what an experience means for the persons involved and their ability to provide a comprehensive description of that experience or perception (Moustakas, 1994). However, phenomenology not only facilitates a description, it is also an interpretive process where the researcher can interpret the meanings of the lived experiences (Bloomberg & Volpe, 2012). The perceptions of the target group are important given that these men may have different experiences, views, and levels of awareness of prostate cancer than African-American

men. Those differences may affect whether or not they are diagnosed and treated in the early stages of the disease. In this study, I investigate participants' beliefs and perceptions of their susceptibility to prostate cancer, perceptions of severity of the disease, perceptions of the benefits and barriers of taking corrective actions, and their confidence in taking action based on the combined models of the health belief model (HBM) and theory of reasoned action (TRA) synthesized as the conceptual framework.

Findings from this study add to the body of knowledge and help address the existing gap in the literature relative to the perspectives, experiences, and beliefs of Afro-Caribbean men. Based on the findings, I also provide recommendations on educational and outreach efforts specifically targeted to Afro-Caribbean men.

Research Questions

Research Question 1: What are the lived experiences of Afro-Caribbean men relative to prostate cancer?

Research Question 2: What are the perceptions of risk, risk factors, prevention, detection, and treatment of prostate cancer?

Research Question 3: To what extent, if any, does culture affect the lived experiences, beliefs, and motivation to act relative to prostate cancer for Afro-Caribbean men?

Conceptual Framework

In order to understand the differences in health belief and practices of people of different backgrounds within a culturally diverse society such as the United States, it is necessary to discuss theories that relate to those beliefs. For this qualitative

phenomenological study, I relied on prior theory and research by using a set of concepts and relationships imbedded within a structure to help piece together data that might otherwise seem unrelated (Maxwell, 2005). I also employed a combination of the HBM and the TRA as a synthesized conceptual framework for this study.

The Health Belief Model

The HBM was developed in the 1950s and explores the relationship between beliefs and behaviors relative to health, while attempting to understand and predict how one would comply with appropriate therapies (Clarke-Tasker & Wade, 2002). The model was first presented with four concepts where it was proposed that a person's health-related behavior depends on their perception of the following key areas (Rosenstock 1974):

1. The severity of a potential illness.
2. The person's susceptibility to that illness.
3. The benefits of taking a preventative action, and
4. The barriers to taking that action.

In an attempt to expand its predictive ability, some researchers who used this model expanded the HBM to include the concept of "Cues for Action" to stimulate behavior, and in 1988, the concept of self-efficacy was added (Rosenstock, Strecher, & Becker, 1988). Bandura (1977) defined self-efficacy as one's belief in his or her capability to perform a certain behavior. According to Rosenstock et al. (1988), the model assumes that individuals are ready for action based on their assessment of their vulnerability and the consequences of having the illness.

The HBM has been used in several similar qualitative studies, including a study by Kleier (2004) who investigated the perceptions of Jamaican and Haitian men regarding prostate cancer. The HBM is a social cognitive model focused on health actions, where behaviors such as seeking screening and complying with medical advice are the result of choices between different courses of action (Poss, 2001). One of the major criticisms of the HBM is that it does not account for cultural or normative factors (Poss, 2001).

The HBM has been used in at least one study that looked at culturally specific factors where future interventions needed to be culturally sensitive (Austin, McNally, & Stewart, 2002). However, Poss (2001) argued that validation of the HBM has been almost exclusively carried out in North America, and its applicability to other cultural settings has yet to be established. For example, a study by Volk and Koopman (2001) that assessed factors associated with condom use in Kenya showed that of the four components, perceived barriers was the only one significantly related to condom use.

Although the HBM is applicable to this study, given that respondents' responses may be strongly influenced by their perception of the four critical areas, the cultural and ethnicity factors associated with this study population limits its applicability even though participants are required to have been residing in the United States for more than 10 years.

The Theory of Reasoned Action

The theory of reasoned action (TRA) is a general theory of human behavior that attempts to explain the relationship among beliefs, attitudes, intentions, and behaviors

(Poss, 2001). Fishbein (as cited by Poss, 2001) noted that the goal of the TRA is to predict and understand behaviors that are directly observable and are under the control of individuals.

One of the main reasons for combining the TRA with the HBM as the conceptual framework is that the TRA allows for a culturally based or culturally influenced study (Poss, 2001). The TRA has been used as the framework for a comparative study of smoking behaviors and attitudes in a Latino group because its concepts enhanced the ability to conduct cross-cultural investigations (Marin et al., 1990). A model synthesizing the TRA and HBM has been used successfully in screening programs, as well as studying the health behaviors and beliefs of culturally different groups (Poss, 2001). According to Poss (2001), when used in combination, the HBM concepts of perceived barriers and perceived benefits are equivalent to the TRA concept of beliefs and evaluations about behavioral outcomes.

The combination of the HBM and TRA is important in the attempt to predict how Afro-Caribbean men behave relative to prostate cancer prevention and management, while bringing clarity and understanding to the concept of cultural competency and health related behavior in the study group. The cultural component is essential primarily because the study topic and research questions are affected to an undetermined extent by the effect of cultural norms, beliefs, and socioeconomic and educational issues that are either determined by, or are a consequence of, the participants' lived experiences.

Nature of the Study

This was a qualitative, phenomenological study that used standardized, open-ended interviews in a one-on-one format. The key concepts studied were the perceptions, experiences, and beliefs of Afro-Caribbean men who reside in the United States relative to prostate cancer. In determining the methodology for this research, I considered a quantitative survey approach but determined that it would not have captured the broad and rich details about each participant that a phenomenological approach would allow.

Using a qualitative phenomenological design facilitated the in-depth exploration of greater details such as how participants perceive and describe information, how they interpret it, judge it, remember it, make sense of it, talk to others about it, and how they relay their experiences and the experiences of others they know relative to the disease (Patton, 2002). I contend that it would be more difficult to capture the detailed information that would be critical to addressing the research questions if a quantitative study was used. I discuss the rationale for using the phenomenological approach in greater detail in Chapter 2.

According to Patton (2002), the standardized open-ended interview format requires careful and thoughtful planning and wording before conducting the interview. However, Patton also noted that it offers opportunities for probing and transitions that can help participants move easily from one question to a related one. While this format does not allow for the flexibility and spontaneity of the informal, conversational type of interview, it is intended to provide more structure and help the interviewer stay on task.

In addition, given the limited time that was allowed for interviews in this study, highly focused questions helped to establish priorities for the interview (Patton, 2002). I collected data from a purposive sample of 13 Afro-Caribbean men who reside in the Minneapolis/St. Paul metropolitan and suburban areas of Minnesota and analyzed those data with the help of the NVivo software tool. Data collected from each interview were transcribed and auto-coded with the help of the NVivo software auto-coding feature. Details of how the software was used are discussed in greater detail later in this paper.

Definition of Terms

The following terms are defined for the purpose of the study:

Acculturation: The process of the adaptation or accommodation of an individual immigrant or immigrant group to a new culture (Roux & Halstead, 2009).

Adenocarcinomas: This is a cancer originating in glandular tissue. The tissues affected are part of a larger category known as epithelial tissue that surround skin, glands, cavities of organs, and others (Mandal, 2013).

Afro-Caribbean: Most Afro-Caribbean people are the descendants of captive Africans held in the Caribbean from 1502 to 1886 during the era of the Atlantic slave trade. Afro-Caribbean Americans originate from the British islands (e.g., Jamaica, Barbados, Grenada, and Trinidad and Tobago) as well as from the French, Dutch, and Spanish-speaking islands (i.e., Haiti, Aruba, Curacao, Cuba, and the Dominican Republic) Caribbean regions. (Stephenson, 2004).

Cultural awareness: The self-examination of beliefs, values, and personal biases (Kratzke & Bertolo, 2013).

Cultural competence: A process of developing cultural awareness, knowledge, and skills (Shen, 2004).

Culturally competent health care: The ability to deliver health care with knowledge and sensitivity to cultural factors that influence the health and illness behavior of an individual, family, or community (Horevitz, Lawson & Chow, 2013).

Cultural knowledge: Acquired to understand other cultural aspects (Kratzke & Bertolo, 2013).

Cultural skills: Abilities used to collect assessment information (Kratzke & Bertolo, 2013).

Benign prostatic hyperplasia (BPH): A noncancerous enlargement of the prostate gland (Beers & Berkow, 1999).

Digital rectal examination (DRE): An examination in which a doctor inserts a lubricated, gloved finger into the rectum to diagnose a variety of maladies, including prostate cancer (Kowalik et al., 2012).

Health belief model (HBM): A theoretical framework for explaining and understanding individuals' responses to health-related matters (Champion & Skinner, 2008).

Heritage consistency: The degree to which a member of an ethnic group identifies with and practices customs common to his or her ethnic background (Spector, 2004).

Obeah: A term used in the West Indies to refer to folk magic, sorcery, and religious practices derived from West African origin (Mantz, 2007).

Prostate cancer: A malignant tumor within the prostate gland (Beers & Berkow, 1999).

Prostate specific antigen (PSA): A glycoprotein produced almost exclusively by the prostate gland. Men with prostatic diseases may have high serum PSA levels because of enhanced production of PSA (Beers & Berkow, 1999).

Theory of reasoned action (TRA): A general theory of human behavior that attempts to explain the relationship among beliefs, attitudes, intentions, and behavior (Poss, 2001).

Assumptions

The following are assumptions that were made in this study as being true and that impacted the design, findings, and conclusions without validation or proof:

1. Participants were assured that their rights would be protected during the data collection process by signing an informed consent form. This form also indicated that confidentiality of their responses would be maintained and no responses would be identified with any particular respondent (Appendix A).
2. The sample of participants in this study was representative of the population to which I wish to make inferences. A purposive sample was comprised of a homogenous group of men of African descent who were originally from the Caribbean and who have resided in the United States for more than 10 years.
3. “Meaning is embedded in people's experiences, and this meaning can be mediated through the investigator's own perceptions” (Simon, 2011). As someone who was diagnosed with prostate cancer, I may be able to reconcile,

understand, and interpret some of the feelings and experiences of study participants.

Scope

The scope of this study focused on developing an understanding of how Afro-Caribbean men perceive prostate cancer, its potential effect on their lives, and their assessment of their risk to the disease. I attempted to address the specific aspect of the research problem relating to the dearth of qualitative data available on Afro-Caribbean men and prostate cancer. It is anticipated that the results from this study will make a contribution to positive social change relative to how Afro-Caribbean men perceive their risk and susceptibility to prostate cancer. The findings may also stimulate the discussion on educational and early detection and preventative strategies targeted to this group.

Delimitations

The purpose of this study was to explore the health beliefs about prostate cancer in a sample of Afro-Caribbean men who reside in the United States. It was not intended to capture how Afro-Caribbean men manage or deal with the disease, as participants were not required to have been diagnosed with the disease. It was also not intended to make assessments of their risk of having the disease because that goes beyond the scope of this research.

The choice of research topic, objectives, and research questions chosen was largely driven by the paucity of information on prostate cancer and Afro-Caribbean men residing in the United States. Participants needed to be Afro-Caribbean men who have lived in the United States for a minimum of 10 years and were within the age range of 40

to 75 years of age. Although the results of this research may not be generalized or transferable to the general Afro-Caribbean male population, the study design allows for possible extrapolation to Afro-Caribbean men who have resided in the United States for more than 10 years (Patton, 2002).

Limitations

There are several limitations to using a phenomenological approach for this qualitative study. First, as the sole researcher, I am responsible for gathering the data, making sense of it, and organizing it into categories or themes. Despite the goal of being objective in my research, as in most qualitative studies, interpretation of what is heard or understood is subject to researcher bias and may not have been exactly what participants meant during the interview process. Interview data are also subject to recall error, reactivity of the interviewee to me, and self-serving responses (Patton, 2002).

Another shortcoming of qualitative studies that use only one method of data collection is the greater vulnerability to errors such as loaded interview questions and biased or untrue responses (Patton, 2002). Although some of the potential problems that might affect the findings and conclusions were discussed earlier in this chapter under Assumptions, it cannot be presumed that they were all eliminated or accounted for.

The ongoing relationship I have with four of the study participants who are part of an Afro-Caribbean community network is an important limitation. I recruited four participants from the Minnesota Cricket Association, a group of which I am a member, and they provided me with contacts from other Caribbean territories. In addition, as an Afro-Caribbean male, I was diagnosed with prostate cancer at a relatively early age. I,

therefore, make my personal relationships, biases, and predispositions explicit, and I provide candid details about my connections with participants later in this paper. I also detail any experiences related to the research that may affect reflexivity, data collection, analysis, and interpretation (Patton, 2002). Greater details on strategies used to minimize such potential biases are discussed in Chapter 3 of this paper.

There were several additional limitations specifically related to the phenomenological study design. The phenomenological approach using interviews generated a large quantity of interview tape recordings, which made the analysis process difficult and exhaustive as the data did not fall into neat categories.

Small sample size is an important limitation, and it can create questions relating to the quality and credibility of the findings as well as the trustworthiness of the researcher. Findings, therefore, can be subjective, not replicable, and cannot be generalized unless the quality of the research meets certain criteria as defined by the reader. However, whether sample size was adequate or not will depend on peer review, consensual validation, and judgment (Patton, 2002). There is also the ethical issue of possibly misrepresenting, distorting, or deleting findings that may have been provided in good faith by study participants. I address how those issues were managed later in this paper.

One final limitation relates to the fact that the Caribbean is made up of many different islands with education and cultural beliefs that may be unique to each island or country. Categorizing people from the Caribbean region as a single group does not necessarily allow for those differences. Furthermore, availability and access to health

care services are different from island to island and may affect how Afro-Caribbean immigrants access those services once they are living in the United States.

Threats to Validity

Patton (2002) noted that the organization and management of data collected can affect the outcome and validity of any study. Factors that present significant threats to validity can compromise the credibility of a research study.

Internal Validity (Credibility)

Validity is the degree to which conclusions can be drawn about a study because of the characteristics of participants, instrument bias, or selection (Polit & Beck, 2008).

Patton (2002) argued that there are several ways to establish credibility. In this qualitative, phenomenological study, I followed a series of methodological steps. The first step was to contemplate the subject matter as it affects me within the context of my lived experiences. As the sole researcher, I make my biases and predispositions explicit and provide candid details relative to my connections with participants and experiences (Patton, 2002). I also devised a sampling plan to ensure that the appropriate subjects are available and willing to answer questions.

In the second step, I presented participants with general open-ended questions that allowed them to explore and express their innermost feelings and perceptions as well as the meaning of those feelings. The third step involved phenomenological reduction where I attempted to grasp a description of meanings and essences of their experiences and perceptions from an open-minded perspective. In the fourth step, I examined

responses for cogent themes. I consciously searched for alternative themes, divergent patterns, and rival explanations that might support alternative explanations.

For the fifth step, once I was satisfied that I had developed the most appropriate themes and meanings, as a form of triangulation, I sought respondent validation and provided participants with the opportunity for final input and necessary corrections to make sure that their intent and meanings were accurately reflected in the descriptions (Maxwell, 2005). The fifth step was the beginning of the analysis process as well as a continuation of the validation process.

Phenomenological inquiry can be categorized into empirical or hermeneutic approaches (Moustakas, 1994). Empirical phenomenology is intended to describe the general characteristics and determine the meaning of a phenomenon. Hermeneutics involve a focus on consciousness and experiences and contains both descriptive and interpretive aspects (Giorgi 2008). The goal of hermeneutics is to describe, understand, and interpret participants' experiences (Tuohy et al., 2013).

The aim of the phenomenological researcher is to accurately describe the phenomenon and refrain from pre-given frameworks by being as factual as possible (Groenewald, 2004). Moustakas (1994) noted that in phenomenological research, the investigator generally has a personal interest in whatever is being investigated and is intimately connected with the phenomenon (p. 59). Given that the hermeneutic approach allows for both descriptive and interpretative aspects within a study, that approach was more appropriate for this qualitative phenomenological study.

External Validity (Transferability)

External validity is the degree to which findings can be generalized or transferred, and sample size is one significant compromising factor (Creswell, 2012). Creswell (2012) posited that the intent of qualitative research is not to generalize findings to individuals outside of those under study. Furthermore, Patton (2002) emphasized that “the validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capability of the researcher than with sample size” (p. 245).

The purposive sampling strategy used in this study was intended to include participants from as many English-speaking Caribbean islands as possible with the desire for extrapolation in mind (Patton, 2002). According to Malterud (2001), although generalization is not generally applicable in qualitative studies, no study, regardless of sampling design, can provide findings that are universally transferable.

With the hope of some transferability in mind, I provided background material, such as demographics and study setting to provide context so that the reader can decide for which situations the findings might provide valid information (Malterud, 2001). Therefore, the design of this study, the assumptions of the research questions, and the reasons for the sampling strategy were made clear so that they might provide an indication of what an adequate degree of transferability could possibly be for the reader (Malterud, 2001).

According to Goetz and LeCompte (as cited by Huberman & Miles, 2002), qualitative studies can gain the potential for applicability to other situations if the

components in the study are well detailed and the theoretical position and research techniques are clearly described. If those conditions are met, other researchers can make their own judgments about how applicable the comparison or transfer can be (Huberman & Miles, 2002).

Significance of the Study

Based on 2008-2009 statistics, there are over 509,200 Afro-Caribbean men over 45 years of age in the United States who may be at risk for prostate cancer (Thomas, 2012). Although this may seem like a small population compared to the overall population of Black men in the United States who may be at risk, researchers such as Kleier (2003) argued that this population of men have a general lack of knowledge of the disease, have misconceptions of the causes of the disease, do not participate in early detection programs, and do not understand the significance of symptoms of the disease. In addition, members of this population may be reluctant to seek medical evaluation partially due to lack of understanding of the consequences of not seeking medical or surgical intervention (Kleier, 2003).

A comprehensive literature search on prostate cancer in Afro-Caribbean men in the United States revealed that only a few studies have documented and discussed how these men view this potentially fatal disease and their susceptibility to it. Of the few qualitative studies on prostate cancer where the focus was on Afro-Caribbean men in the United States (Kleier, 2003; Lee et al., 2012; Magnus, 2004; Parchment, 2004), most researchers did not assess the views and perceptions of study participants.

This phenomenological study is significant for several reasons. It provides informed documentation of how Afro-Caribbean men perceive, experience, and believe about the disease and further highlights the level of awareness of this ethnic group. It also provides guidance on whether there needs to be educational and promotional efforts targeted to this group and whether additional research needs to be done to increase awareness of this disease in this high-risk population.

Implications for Further Research

In a critical review of studies on migration and prostate cancer, Angwafo (1998) concluded that there needs to be additional international and cross-cultural epidemiologic studies to investigate the incidence, knowledge, and perceptions of prostate cancer in ethnic populations. Kleier (2003) conducted a literature review that looked at prostate cancer in Black men of African descent and concluded that prostate cancer interventions developed for African-American men may not be effective for Afro-Caribbean men. Moreover, one qualitative study conducted by Nanton and Dale (2011) investigated the perceptions and experiences of treatment and care of Afro-Caribbean men in the United Kingdom relative to prostate cancer; but no similar studies have been conducted in the United States.

Given that researchers have found differences in incidence, knowledge, experience, and other issues related to the disease amongst men of African descent residing in different countries, one cannot presume that the perceptions, experiences, and beliefs of this study population will be the same or even similar to those of African-American men, a group that has been studied more extensively. Consequently, there is a

gap in the literature relative to those perception and beliefs which this study sought to address.

Implications for Social Change

Results from this study provide a window into how Afro-Caribbean men think about prostate cancer and assess their risk to the disease. According to Pedersen, Ames, and Ream (2012), men of African descent bear the highest burden of the disease, yet little is known about where Afro-Caribbean and Black African men get prostate cancer information. There have also been limited efforts to ensure that this high-risk group of Afro-Caribbean men has access to relevant disease information (Pedersen et al., 2012).

In addition, the findings will add to the body of knowledge by partially addressing the existing gap in the literature on the health beliefs of Afro-Caribbean men towards prostate cancer, thereby increasing the awareness of prostate cancer in this understudied group. Given that the findings of this study suggest that there is an association between Afro-Caribbean men's beliefs, experiences, perceptions, and the likelihood of seeking prostate cancer education, early detection, and treatment, readers of this study can determine whether these findings may be potentially applicable to other situations. That determination will be strongly influenced by the design of this study, the assumptions of the research questions, the reasons for the sampling strategy, and the description of the theoretical position and research techniques (Malterud, 2001).

Finally, the results of this study suggest that there needs to be educational information and early detection strategies for prostate cancer specifically targeted to Afro-Caribbean men.

Summary

The incidence of prostate cancer in African-American men has been well documented as one of the highest in the world. However, several studies have suggested that for Afro-Caribbean men, men of African descent who reside in their native countries, and Black men who have immigrated to the United States and the United Kingdom, their incidence may be either similar to or higher than that in African-American men. Based on the studies mentioned in Chapter 1, there is general agreement that not enough data exist to conclude what the true incidence rates are for Afro-Caribbean men. Depending on the sources, either African-American or Afro-Caribbean men from Jamaica, Martinique, or Guadeloupe have been noted as having the highest incidence of prostate cancer in the world. In addition, few qualitative studies exist that look into how Afro-Caribbean men perceive their risk and susceptibility to the disease. Therefore, it has been difficult to target this group strategically for early detection efforts.

The HBM (Janz & Becker, 1984; Rosenstock, 1974, 1990; Rosenstock et al., 1988), and the TRA model (Poss, 2001) were selected as a synthesized conceptual framework for this study. That combination assisted in explaining the key concepts and variables of this study and any presumed relationships between them. The incorporation of a model that looks at the relationship between beliefs and behaviors relative to health, culture, ethnicity, and health care from a culturally sensitive perspective was viewed as being central to addressing the research questions in this study.

In this chapter, I discussed the qualitative, phenomenological design of this study. I also outlined the data collection methods, the limitations, delimitations, scope, and

assumptions that were essential in helping to arrive at a thorough understanding of how those components impacted the design, findings, and conclusions. This study is significant because researchers of Afro-Caribbean men and prostate cancer have documented a general lack of knowledge of the disease, misconceptions of the causes of the disease, and a lack of understanding of the significance of symptoms (Kleier, 2003, 2004). Kleier (2004) also argued that there is an overall paucity of research data in this group. In this research, I sought to partially fill the gap in the qualitative discussion of how Afro-Caribbean men view prostate cancer and their susceptibility to it. It is anticipated that the findings from this research will encourage more Afro-Caribbean men to seek preventative measures through early detection testing by way of DRE exams and PSA screening.

Transition Statement

In Chapter 1, I discussed the background of prostate cancer from a world view perspective. I focused on the published evidence that emphasized the significance of the disease to men in general and the demonstrated difference in incidence and mortality based on race, ethnicity, and geographic locale. Those factors were central to the topic and research questions on which this study was based. In Chapter I, I also discussed the etiology of prostate cancer and the difficulty in determining the reasons for differences in incidence and mortality rates in different races and locales, with particular emphasis on African-American and Afro-Caribbean males. In addition, I outlined the conceptual framework on which the research is based and briefly discussed the purpose, nature, and significance of this study as well as its limitations, scope, and assumptions.

In Chapter 2, I focus on a comprehensive review of the published literature on prostate cancer with an emphasis on studies of men of African descent in general, but more specifically, on studies of prostate cancer in Afro-Caribbean men in the United States, Europe, and the Caribbean. Given that there are very few qualitative studies conducted on prostate cancer and Afro-Caribbean men in the United States and the literature review incorporates data on Afro-Caribbean men living in the Caribbean and Europe as well as qualitative studies of African-American men. In Chapter 2, I also discuss the conceptual framework in greater detail, the etiology of the disease, global patterns and trends of prostate cancer, and a review of the methodology that was used for this study.

Chapter 2: Literature Review

The purpose of this qualitative, phenomenological study was to investigate the experiences, perceptions, and beliefs of Afro-Caribbean men who reside in the United States relative to prostate cancer. The ultimate objective was to determine if those experiences, perceptions, and beliefs affect, and to what extent, whether or not this ethnic group seeks education, early detection, and treatment for a disease that is the second largest cancer killer of Black men in America. Several studies have shown that Afro-Caribbean men are at high risk for prostate cancer but may not be aware of that risk. In addition, there is a general lack of knowledge of prostate cancer among Afro-Caribbean men (Kleier, 2004). Moreover, most Afro-Caribbean study participants have misconceptions of the causes of the disease, did not participate in early detection programs, and when they experienced symptoms, they either did not understand the significance of those symptoms or were reluctant to seek medical evaluation (Kleier, 2003). Consequently, this population is more likely to be diagnosed when the disease is in its later stages, making treatment options more limited and increasing the likelihood of dying from this potential killer.

The risk of prostate cancer is higher in westernized men of African descent than in any other ethnic or racial groups (Hsing et al., 2000; Wild, Fischbacher, Brock, Griffiths, & Bhopal 2006). Among all ethnic and racial groups in the United States, African-American men have the highest prostate cancer incidence, morbidity, and mortality (Odedina et al., 2008). However, some studies have also shown that there is a disproportionate burden of prostate cancer among Caribbean men of West African

descent (Ben-Shlomo et al., 2008; Glover et al., 1998; Kheirandish & Chinegwundoh, 2011). Despite the high incidence of prostate cancer amongst Afro-Caribbean men, there are very few studies that focus on how this group perceives their risk, susceptibility, and mortality relative to the disease.

The reasons for the disparity are not well understood (Zeigler-Johnson, 2008), but according to Kleier (2003), there is speculation that the possible causal links may be genetic, dietary, and socioeconomic. Zeigler-Johnson et al. (2008) also suggested that environmental exposure, one's social environment and behavior, and a biological difference in the way prostate cancer presents itself in men of African descent may help account for the ethnic disparity. Kheirandish and Chinegwundoh (2011) conducted a literature review of studies from the United States and the United Kingdom and theorized that the behavior of prostate cancer is similar in different ethnicities, and therefore equal access to urological services can result in equal outcomes.

Angwafo (1998) postulated that racial and geographic differences in the incidences of prostate cancer seem to suggest that the environment may be a causal factor. The author theorized that heredity may contribute to susceptibility to exogenous risk factors in ethnic groups who live in the same environment. Angwafo also argued that wide variations in incidence rates among the same ethnic groups who reside in different areas of the world, as well as rates that have changed for men who migrated to the United States, suggest that prostate cancer risk factors are environmental. He further asserted that migration and environmental patterns seem to influence the intra- and interracial differences and mortality rates worldwide. Those factors may account for the

significant increases in incidence among first-generation immigrants and may modify prostate cancer risk for different racial groups (Angwafo, 1998).

For Afro-Caribbean men who reside in the United States, there is little information, and statistics differ on whether the incidence, morbidity, and mortality of prostate cancer are similar to those of African-Americans. In addition, studies on the experiences, perceptions, and beliefs of Afro-Caribbean men who reside in the Caribbean, Europe, and the United States relative to prostate cancer are also limited. For example, of the studies identified, the only ones conducted in the United States that focused on Afro-Caribbean men were those by Kleier (2003), Lee et al. (2012), Magnus (2004), Odedina et al. (2009), and Parchment (2004).

Chinegwundoh et al. (2006) sought to determine if there are ethnic differences in risk and presenting factors amongst Afro-Caribbean, South Asian, and European men. The authors concluded that African Caribbean men had a three-time greater risk of having the disease than European men. The findings of Nanton and Dale (2011), who investigated the perceptions and experiences of treatment relating to prostate cancer in Afro-Caribbean men in the United Kingdom, suggested that there needs to be a more culturally sensitive approach to the information process. Kleier (2003) conducted a literature review that looked at prostate cancer in Black men of African descent and concluded that prostate cancer interventions developed for African-American men may not be effective for Afro-Caribbean men.

In Chapter 2, I focus on a comprehensive review of the published literature on prostate cancer with an emphasis on studies of Afro-Caribbean men in the United States,

Europe, and the Caribbean. As part of the review, I present data related to the disease in African men, men of African descent, and men of other races and ethnicities. These studies are presented from a comparative perspective so that the information on Afro-Caribbean men can be placed in perspective. However, the majority and focus of this review is on Afro-Caribbean men. I also discuss the conceptual framework that forms the foundation for this study, the etiology of the disease, global patterns and trends relative to prostate cancer, and a synopsis of the methodology that is used for this study.

Literature Search Strategy

The literature review for this study includes peer-reviewed articles and books that were secured using search terms such as *prostate cancer, African-American, African Caribbean, Afro-Caribbean, ethnic, Health Behavior Model, multidimensional health locus of control, genetic susceptibility, self-efficacy, theoretical construct, conceptual framework, disparities, Caribbean migration, survival, morbidity, mortality, prostatic diseases, research, epidemiology, risk factors, etiology, diet, prostate specific antigen, PSA, Africa, United Kingdom, European, Africa, Asian, screening, global, trends, patterns, heritage assessment, heritage consistency, cultural competence, cultural diversity, cancer statistics, benign prostatic hyperplasia, NVivo, and qualitative*. Those search terms used alone or in combination were valuable in identifying published peer-reviewed qualitative studies on prostate cancer and African-American men; published peer-reviewed studies relating to prostate cancer in Afro-Caribbean men living in the United States, the Caribbean, and the United Kingdom; published peer-reviewed studies of prostate cancer in men of other races and ethnicities; and published studies of trends,

incidence, and global patterns of prostate cancer in different ethnicities worldwide. Many of the most useful articles chosen were identified from the reference sections and citations provided in other articles. It is important to note that several of the citations are greater than 5 to 10 years old primarily because the information was seen as important to the overall discussion and there was no more recent information available.

The key databases used included The Walden Library EBSCO database, The National Center for Biotechnology Information, The National Library of Medicine, The Food and Drug Administration, CINAHL Plus, Medline, Nursing and Allied Health, Google Scholar, and PubMed. In addition, statistical and trend data on incidence and death rates from prostate cancer of all men in the United States, of African-American men in the United States, of Black men in Europe, of other ethnicities, national government data on prostate cancer, and associated national and state statistics were all secured from the following sources:

- <http://www.gpo.gov/fdsys>. This database covers all three branches of government.
- <http://catalog.gpo.gov>. This is a catalog of U.S. Government publications that shows which documents are available in print or electronically.
- <http://www.United States.gov>.
- National Cancer Institute. (2013). Quick cancer profiles.
- National Cancer Intelligence Network. Cancer incidence and survival by major ethnic group, England, 2002-2006.
- Cancer Research U.K., 2008.

Conceptual Framework

The conceptual framework for this study is a synthesis of the HBM and the TRA model. In order to understand the differences in health belief and practices within a culturally diverse society such as the United States, it is necessary to discuss theories that relate to those beliefs. The population in the United States is becoming increasingly racially and ethnically diverse, and by the year 2050, ethnic and racial minority groups will comprise nearly half of all Americans (U.S. Bureau of Census, 1996).

The Health Belief Model

The HBM attempts to explain, understand, and predict people's behavior relative to preventative health practices. Some social cognitive theorists argue that in order to facilitate a change in behavior, a person not only needs to have the knowledge and skill that is required to self-regulate that behavior but they must also believe that they have the ability to initiate and practice new behaviors (Champion & Skinner 2008). The main constructs of the HBM are perceived severity, perceived susceptibility, perceived benefits, and perceived barriers, which can be used either individually or in combination to explain health behavior (Hayden, 2009).

Perceived severity. The construct of perceived severity relates to the belief of the seriousness of the disease, and while this may be based on medical information, it has a lot to do with an individual's perception of the difficulties a disease would create, or the effect it would have on their life (Hayden, 2009). In a study by Robinson, Ashley, and Haynes (1996), African-American men stated that they would be willing to undergo screening and clinical trials if it would increase their likelihood of living longer or

preventing a terminal illness. In terms of mortality rates, the data have shown that the severity of prostate cancer is manifested to a greater extent in African-American men than in Caucasian men. For example, Haas and Sakr (1997) found that the 5-year survival rate for African-American men diagnosed with prostate cancer is 75% compared to 90% for Caucasian men.

Perceived susceptibility. Hayden (2009) contended that a perception of susceptibility to disease is linked with healthier behaviors, and the greater the perceived risk, the greater the likelihood of modifying behaviors to reduce that risk. He also argued that the perception of susceptibility alone is often not enough to influence behavioral change. However, when the perception of susceptibility is combined with a perceived seriousness, it often results in a perceived threat or risk to one's wellbeing and can result in positive behavioral modification (Hayden, 2009).

Perceived benefits. The construct of perceived benefits relates to one's opinion of the usefulness of a behavior in reducing risk of developing a disease (Hayden, 2009). Rosenstock (1990) emphasized that although a person accepts his or her susceptibility to a disease considered to be serious and is likely to have a behavioral change, he or she would not be expected to take any recommended action unless that behavior will decrease the chance of developing a disease.

Perceived barriers. This construct is an individual's evaluation of the obstacles that may prevent him or her from adopting a new behavior. Hayden (2009) posited that in order for a person to adopt a new behavior, he or she needs to believe that the benefits outweigh the consequences of continuing the old behavior. Rosenstock (1990) suggested

that individuals go through a nonconscious, cost-benefit analysis as they weigh how effective a new behavior may be against the perceptions that it may be expensive, dangerous, painful, inconvenient, and so forth.

Modifying variables. The four constructs of the HBM are modified by demographic, social, psychological, and structural variables. The influence of variables such as culture, past experiences, and motivation on personal perceptions can have an indirect effect on whether or not a person chooses to modify their existing behavior (Hayden, 2009). According to Spector (2004), race and ethnicity are mentioned most often when there is a difference in race and class between providers and patients. In the case of prostate cancer, sociodemographic factors such as age, race, ethnicity, income, and the level of education are believed to have an effect on behavior by influencing the perception of susceptibility, severity, benefits, and barriers (Rosenstock, 1990).

Cues to action. Cues to action are described by Hayden (2009) as events, people, or things that motivate people to change behavior. Weinrich, Greiner, Reis-Starr, Yoon, and Weinrich (1998) provided the example of African-American men seeing a fellow church member with prostate cancer as a significant cue to action for African-American men to attend prostate cancer education programs.

Self-efficacy. Bandura (1977) defined self-efficacy as “the conviction that one can successfully execute the behavior required to produce the outcomes” (p.79). He emphasized that there is a clear distinction between self-efficacy and outcome expectation, which he defined as a person’s estimation that a given behavior will lead to a certain outcome. Hayden (2009) surmised that people generally will not attempt to do

something unless they think they can accomplish it. Consequently, for behavioral change to succeed, people must feel threatened by their past or current behavioral pattern, believe that change will be beneficial, and perceive that they will be competent and able to make that change (Rosenstock, 1990).

Criticisms of the HBM. According to Rosenstock (1990), some critics hold that the belief-behavior relationship has never been uniformly established, and both individual and socioenvironmental factors should be targeted for health interventions. However, Rosenstock posited that it has seldom been argued that beliefs are sufficient conditions for action and behavioral change. Rosenstock (1990) also noted that critics argued that alternative approaches may be necessary because direct attempts to modify behavior are often unsuccessful. However, he countered that criticism by emphasizing that it may be difficult to interpret such failures as a deficit of HBM since the model was never put forward as a strategy for change, but rather as a tactic that should be part of a broader view of belief change (Rosenstock, 1990).

Rosenstock (1990) indicated that another criticism of the HBM is that the victim may be blamed because the model focuses on the individual determinants of health behaviors. However, he argued that within the model, it is possible to assign blame for health problems to factors outside of the individual so that although the individual is not blamed for the problem, he or she is expected to assume responsibility for the solution (Rosenstock, 1990).

One of the major criticisms is that the HBM does not account for normative or cultural factors (Poss, 2001). Within the context of this study, I attempted to minimize

that shortcoming by using a synthesis of the HBM and TRA as the conceptual framework.

Effectiveness of the HBM. Janz and Becker (1984) summarized results from 46 studies that used the HBM. The authors concluded that those studies provided substantial empirical evidence supporting HBM dimensions as important contributors to explaining and predicting individuals' health-related behaviors. When compared to other models of health-related behaviors, the HBM was determined to be superior in terms of the attention and collaboration given to those behaviors (Janz and Becker, 1984).

Theory of Reasoned Action

The TRA was developed by Fishbein and Ajzen (as cited by Poss, 2001), where it is suggested that people choose to engage in behaviors that are likely to result in desirable outcomes and consider the consequences of alternative behaviors before engaging in them (Poss, 2001). In the TRA, behavioral intent (BI) is derived from two factors: (a) attitude toward the behavior, and (b) subjective norms, which are perceived social pressures associated with the behavior (Hae-Kyong, Ellinger, Hadjimarcou, & Traichal, 2000). According to proponents of the TRA, only beliefs that are foremost in a person's thoughts are determinants of attitude, and the ability of attitude and subjective norms to predict behavior depends on the strength of the relationship between intention and behavior (Poss, 2001).

The TRA has been applied in several health behavioral studies. For example, Alder, Kegeles, Irwin, and Wibbelsman (1990) used the TRA as the conceptual model in a prospective study of methods of contraceptive use in adolescents. The authors

concluded that attitudes and social norms significantly contribute to adolescents' decision-making about contraception. Lierman, Young, Kasprzyk, and Benotiel (1990) studied the ability of the TRA to predict breast self-examination in a retrospective study. Pearson correlation coefficients were significant between the major components of the TRA and breast self-examination in the Lierman et al. study, and the strongest correlation was between intention and actual breast self-examination.

Criticisms of the TRA. The goal of most health care researchers is to understand behaviors and one of the main criticisms of the TRA is that it focuses on intentions instead of behavior (Poss, 2001). The TRA methodology has also been determined to be time consuming for studying complex behaviors because measures of each behavioral component must be created. Consequently, many researchers avoid using this procedure and lose the benefit of the culturally-based perspective on behavior it allows (Poss, 2001).

Combining HBM and TRA

The commonality between the HBM and TRA is primarily based on the notion that behavior depends on the value individuals place on an outcome, as well as their assessment of the probability that a given action will result in that outcome (Poss, 2001). Although various studies have not formally combined the TRA and HBM into one new model, a few studies such as one by Manfredt, Lacey, Warnecke and Potraitis (1998) looked at the sociopsychological correlates of smoking cessation among African-American women. Russell and Champion (1996) examined the health beliefs and social influence in home safety practices of mothers with preschool children.

The primary reason for using a synthesized model as the conceptual framework in this qualitative phenomenological study is that the TRA allows for a culturally-based relevance and perspective that is lacking in the HBM given that demographic variables, social support, and personality factors that can be influenced by cultural differences. That is an important consideration given the cultural difference of this diverse study group, and the TRA will add credibility to the use of a framework that has greater applicability to this qualitative, phenomenological study.

Cultural Phenomena Affecting Health

Roux and Halstead (2009) noted that concepts of health and healing are rooted in culture. There is significant scientific evidence that cultural practices affect an individual's behavior as it relates to promoting, maintaining, and restoring health. Culture also affects how, when, and with whom individuals seek help for prevention and treatment of various conditions and diseases (Roux & Halstead, 2009). Bandura (1982, 1986) posited that the concept of self-efficacy is the expectation that a person is capable of performing a behavior in a particular situation. However, for individuals from different cultures who are immersed in the health care system of the dominant culture, confounding variables of culture, race, ethnicity, and socio-economic factors impact the perception of susceptibility, severity, benefits, and barriers.

It is therefore important to incorporate a discussion of cultural competence and its effect, on not only the perceptions of Afro-Caribbean men, but also how the level of acculturation or adherence to traditional ethno-cultural beliefs and practices affect those

perceptions and the likelihood of engaging in prostate cancer prevention or education initiatives.

The attitudes towards prostate cancer of Afro-Caribbean men who have immigrated to the United States may be strongly influenced by heritage consistency and health traditions, as well as cultural phenomena that affect their health. The concept of heritage consistency implies that the more a person identifies with their traditional heritage, the more likely they will keep their ethnocultural traditional health beliefs and practices (Spector, 2002). Heritage consistency theory was developed to describe the extent to which one's lifestyle reflects their traditional culture (Spector, 2002). According to Spector, the term "traditional" is used to describe ethnocultural and religious beliefs that have been handed down through generations.

Spector (2002) contended that heritage consistent means identifying with one's traditional heritage and observing or engaging in the health practices and beliefs of that traditional culture. Conversely, heritage inconsistent indicates identification with the dominant culture and observance with the health beliefs and practices of that dominant belief system. However, a person can possess value characteristics of both a traditional culture and an acculturated heritage. Although this is a qualitative study with limited transferability, the conceptual framework identified can facilitate the application and generalization of culture-specific information to sociological and anthropological reasoning relative to prostate cancer in the targeted Afro-Caribbean population in the United States (Spector, 2002).

Literature Review Related to Key Variables and Concepts

Prostate cancer is now the most common non-skin cancer diagnosed and the second cause of deaths in men in most western countries (Hsing et al., 2000). Yet there are many unanswered questions related to the etiology, development and treatment of this disease.

Etiology of Prostate Cancer

Despite many epidemiologic studies performed in the last decade, a definite cause of prostate cancer has not been determined. Most prostate tumors are adenocarcinomas and therefore they share several common features with other prevalent epithelial cancers such as breast and colon cancer (ACS, 2013). It has been established that the prevalence of both clinical and histologic prostate cancer increases with age, and after 50 years of age, both the incidence and mortality increase at an almost exponential rate (Pienta & Esper, 1993). Although the clinical incidence of prostate cancer is different in different geographic areas, several studies such as one by Dhom (1983) have shown that the presence of histologic cancer is very similar regardless of geography.

Factors that affect histologic cancer. It has been shown that the presence of histologic cancer increases with age, and data from several countries show that 15 to 30% of men over 50 years old have histologic evidence of prostate cancer. That percentage further increases to 60-70 by the age of 80 years as evidenced by autopsies (Dhom 1983). According to Carter, Piantadosi, and Isaacs (1990a), if the development of clinically evident cancer is initiated partly by histologic cancer, then the data suggest that the

initiation event may occur at approximately the same rate regardless of place of birth or race.

Study data by Carter et al. (1990a) have demonstrated that although there is a significant difference in the clinical presentation of prostate cancer between Japanese and American men, histological age-specific prevalence is similar in Japan and the United States. These data and the observation that immigrants who move from prostate cancer low-risk areas to the United States or Europe gradually assume the higher risk of the area to which they migrated suggest that although the initiation rate may be the same, the rate of disease progression may be different. Pienta and Esper (1993) therefore postulated that the presence of histologic cancer may be related to age, but other risk factors may increase or otherwise alter the development of the disease.

Signs and Symptoms of Prostate Cancer

Prostate cancer generally does not show any signs or symptoms in the early stages of the disease. As the disease progresses, men may have urinary issues such as inconsistent flow, inability to urinate, difficulty starting and stopping urination, an urgent and frequent need to urinate, and pain or other discomfort when urinating. Advanced prostate cancer can metastasize to bones causing significant pain in the hips, spine, ribs, or other areas (ACS, 2012).

Prevention Strategies

Meehan (2002) posited that prevention strategies for prostate cancer include primary, secondary, and tertiary tactics. Primary prevention should be targeted to

individuals who do not have symptoms by reducing or eliminating the risk, primarily through health promotion strategies.

Ross et al. (2011) argued that there is a need for studies which focus of how cancer-free African-American men acquire or seek knowledge about prostate cancer prevention, and how that knowledge affects their behavior. Such a need exists for other ethnic groups such as Afro-Caribbean men which this study explores. Secondary prevention focuses on reducing the risk of the disease in individuals who are considered to be in high-risk groups and involves early diagnosis, early detection, screening, and treatment of early-stage disease. Tertiary prevention is aimed at minimizing morbidity by preventing or managing complications from the disease (Meehan, 2002).

Risk Factors

According to the American Cancer Society (ACS), the only well-established and agreed-upon risk factors for prostate cancer are increasing age, race, and family history (Meehan, 2002; ACS, 2012).

Family history. Researchers such as Cannon, Bishop, Skolnick, Hunt, Lyon, and Smart (1982) have postulated that although the molecular genetics of prostate cancer is poorly understood, inherited factors are believed to account for 42% of the risk of prostate cancer. Cannon et al. have also shown that men with first-degree relatives who are diagnosed with prostate cancer have a higher or increased risk of developing the disease than those without affected relatives. Carter, Carter, and Isaacs (1990b) have also shown that men with a history of a father or brother with prostate cancer are twice as likely to develop the disease as men without affected relatives. Many experts therefore

suggest that men with a positive family history of prostate cancer should initiate screening at an earlier age.

Race/ethnicity. Both incidence and mortality data show wide differences in prostate cancer among various races. The ACS (2012) was even more specific in their assessment of race as a risk factor, and listed African ancestry as a distinct risk factor rather than the broad category of race/ethnicity. It is unclear if the incidence and mortality rates are different among races because of genetic or environmental factors, but migration studies have demonstrated that men from lower incidence areas take on the risk of the country they migrate to (Meikle & Smith, 1990). Unfortunately, confounding factors such as differences in life expectancy such as in Haiti where men have a life expectancy of 61 years (WHO, 2011), diet, and socio-economic status make it difficult to determine the reasons for these differences (Meikle & Smith, 1990).

The Surveillance, Epidemiology, and End Results Program (SEER) as well as census data show that African-American men have a higher incidence rate of clinical prostate cancer than Caucasian men regardless of education or socioeconomic status (Baquet, Horm, Gibbs, & Greenwald, 1991). In addition, African-American men are diagnosed with later-stage prostate cancer with a worst prognosis and lower 5-year survival rates. According to Whittemore, Keller, and Betensky (1991), if the prevalence of histologic prostate cancer is essentially the same in different racial populations as shown by Dhom (1983), then African-American men are either more susceptible to prostate cancer-promoting agents, or they are exposed to different promoting agents.

Whittemore et al. (1991) contended that the transformation rate from histologic to clinically evident prostate cancer is similar for Caucasian and African-American men. Those data seem to suggest that the racial differences in prostate cancer incidence may be partially accounted for by earlier cell transformation in African-American men and possibly all men of African descent (Whittemore et al., 1991).

Socioeconomic factors. It has been suggested that socio-economic factors are a possible reason for the difference in incidence and mortality between African-Americans and Caucasian Americans. Using SEER data, Baquet et al. (1991) found that there was no statistical association between socioeconomic status and prostate cancer incidence. Baquet et al. also found no correlation between prostate cancer incidence and educational level. In general, the data seem to suggest that socioeconomic status is not an important risk factor for prostate cancer.

Dietary fat. Several epidemiologic and migrant studies have associated diet with prostate cancer (Cannon et al., 1982). Researchers such as Dhom (1983) theorized that the association may partially explain why the clinical incidence is higher in “Western” societies even though histologic cancers occur at similar frequency around the world. According to Pienta and Esper (1993), there seems to be an overall association between a high intake of dietary fat and a higher risk for developing prostate cancer, primarily because of its effect on endogenous hormones that decrease circulating testosterone. Barnetson (as cited by Pienta & Esper, 1993), theorized that diet may be associated with prostate cancer by activating latent lesions that are part of all geographical areas.

However, this theory has been disputed by Belpomme and Irigaray (2011) who did not find any correlation between dietary fat consumption and prostate cancer incidence.

Genetics. Kheirandish and Chinegwundoh (2011) posited that differences in prostate cancer incidence rates between races and ethnicities suggest genetic involvement and may partly account for the higher risk seen in family members and ethnicities such as African-American men. Ben-Shlomo et al. (2008) also noted that similar rates seen for Black Caribbean men, African-American men, and African men in the United Kingdom suggest a common genetic etiology of the disease.

As it relates to younger men, Ben- Shlomo et al. (2008) theorized that the risk that may be attributed to genetic factors could be as high as 43%. However, the author also emphasized that although genetic factors may be important, the increase in rates among ethnic groups that have migrated from low-to high-risk areas suggests an important association between genetics and environment. Ben- Shlomo et al. (2008) further suggested that genetics may play a role in the development of prostate cancer, while Zeigler-Johnson et al. (2008) concluded that the genetic contribution to the disease risk is well established.

Vitamin deficiency. Chen and Holick (2003) concluded that an increase in the incidence and mortality of prostate cancer they found in their study was associated with both limited exposure to sunlight and vitamin D deficiency. Although deficiency or reduction in vitamin D synthesis in Black men's skin has not yet been shown, Chen and Holick postulated that reduction in the synthesis of vitamin D might be linked to higher prostate cancer rates in Black men. Those findings seem to support the use of vitamin D

therapies for prostate cancer as a second-line therapy, and similar to prostate specific antigen (PSA) screening, vitamin D tests should be performed annually in men over 30 years, especially in African-American men and indoor workers (Chen and Holick (2003).

Hormonal factors. The implication of hormonal factors has been proposed as one possible explanation for the racial variation in prostate cancer incidence. African-American men have a 13% higher level of bioavailable testosterone than Caucasian men and may be exposed to higher levels of estrogen in utero (Giovannucci, 1996). In a study of the association of bone mineral density (BMD) in Afro-Caribbean men and prostate cancer, Bunker et al. (2006) concluded that high BMD was associated with prostate cancer among older men, and the risk of prostate cancer increased with increasing BMD in men aged 65 to 79 years of age.

Sexual activity. In a study by Hennis et al. (2013), the authors examined the association of sexual behaviors and prostate cancer in Barbadian men. The data showed that there is an increased risk of prostate cancer associated with sexual activity onset at an early age. The researchers also found an increased risk of high-grade prostate cancer with an increase in the number of lifetime partners. However, Hennis et al. (2013) emphasized that it is uncertain how these findings influence prostate cancer development and clinical outcomes.

Other suggested risk factors. Studies examining the role of occupation, cadmium exposure, smoking, infectious agent, vitamin A, vasectomy, and benign prostatic hyperplasia (BPH) have shown mixed or inconclusive results (Pienta & Esper (1993). Apart from the role of vasectomy which seem to slightly increase the risk for

development of prostate cancer, only vitamin D, high BMD, and dietary fat intake have been shown to play a possible role in the cause of prostate cancer (Pienta & Esper, 1993).

Pienta and Esper (1993) concluded that based on a review of several studies of risk factors for prostate cancer, it appears that the disease results from an interplay between genetics, endogenous hormones and environmental influences. However, it is important to once again emphasize that the only established and agreed upon risk factors for prostate cancer are age, race/ethnicity, and family history (Meehan, 2002; ACS, 2012).

Prostate Specific Antigen (PSA)

Between 1989 and 1992, there was a 61% increase in the age-adjusted incidence rates of prostate cancer in U.S. Caucasian men, and a 65% increase in African-American men (Merrill, Potosky, & Feuer, 1996). The authors theorized that this increase was primarily because of PSA testing. Between 1992 and 1993, incidence rates fell 14% for Caucasian males, but rose an additional four percent for African-American men (Merrill et al., 1996). Merrell et al. speculated that the reasons for the decrease among White men may have been a decline in the use of PSA testing. The authors also reported that the reasons for the increase among Black men are unknown and further research needs to be done (Merrill et al., 1996).

Effectiveness of the PSA test. Prostate cancer researchers still debate on the effectiveness of the PSA test for reducing deaths from prostate cancer, primarily because the results from studies have been mixed. No randomized trial data currently exist that show a direct link in the reduction in prostate cancer mortality to PSA testing (Allen et

al., 2007; United States Preventative Services Task Force, 1996). In addition, there are several possible harms associated with PSA testing such as false positive results, unnecessary biopsies, and possible complications that all need to be balanced with the potential reduction of prostate cancer morbidity and mortality (U.S. WHO Preventative Services Task Force, 1996). Despite the lack of broad agreement on the efficacy and outcomes relating to prostate cancer screening, PSA testing continues to be the primary recommended screening test for possible detection of early prostate cancer.

Recommendations regarding PSA testing. To underscore that lack of consensus on prostate cancer screening recommendations, the National Cancer Institute (NCI), the United States Preventative Services task Force (1996), and the Center for Disease Control (CDC) do not recommend routine testing for prostate cancer at this time because there are insufficient data to recommend for or against routine testing for early prostate cancer (NCI, 2005). However, the ACS and the American Urological Society recommend that all men should be tested at age 50, but African-American men and men with a close relative who was diagnosed with prostate cancer before the age of 65 should be tested at the age of 45 using PSA screening along with a digital rectal examination (DRE) (Oliver, 2007).

Global Patterns and Prostate Cancer

Prostate cancer is the second most frequently diagnosed cancer among men, and the sixth leading cause of death in males worldwide (Ferlay et al.,2010). According to Jemal, Center, DeSantis, and Ward (2010), the highest incidence rates have been found in North America, Oceania, and Northern and Western Europe. More than 50% of cases

and deaths are expected to occur in the more developed countries, and it is estimated that in Europe and the United States, as many as 23 to 42% of prostate cancer cases may be due to over diagnosis because of increased PSA testing (Jemal et al., 2010).

Figure 1 shows the rates by country according to the International Agency for Research on Cancer (IARC) (2010) world age-adjusted incidence rates per 100,000 population statistics from Cancer Research United Kingdom (2008). Those data show that the Caribbean has a lower incidence rate than Australia/New Zealand, Western Europe, Northern America, and Northern Europe. Africa is noted as amongst the lowest in the world.

The data shown in Figure 1 are inconsistent with the findings by researchers such as Quinn and Babb (2002) who looked at international patterns and trends in prostate cancer incidence, survival, and mortality. Quinn and Babb noted that the United States and Canada have the highest incidence rates in the world by far, and all European rates were far below those in the United States. Hsing et al. (2000) in their comparison of international trends and patterns in age-adjusted incidence and mortality rates of prostate cancer from 15 countries between 1973-1992, pointed out that U.S. Blacks were ranked #1 at 137, U.S. Whites # 2 at 100.8, Canada # 3 at 84.9, Sweden #4 at 55.3, and Australia #6 at 53.5 per 100,000.

Prostate cancer incidence rates have been decreasing in the United States, Canada and Australia after increasing dramatically between the late 1980s and early 1990s due to the popularity and use of PSA testing (Baade, Youlten, & Krnjacki, 2009). However, Baade et al. noted that incidence rates in the United Kingdom and some other European

countries have seen a continuous rise in incidence as PSA testing has gained more popularity in those countries

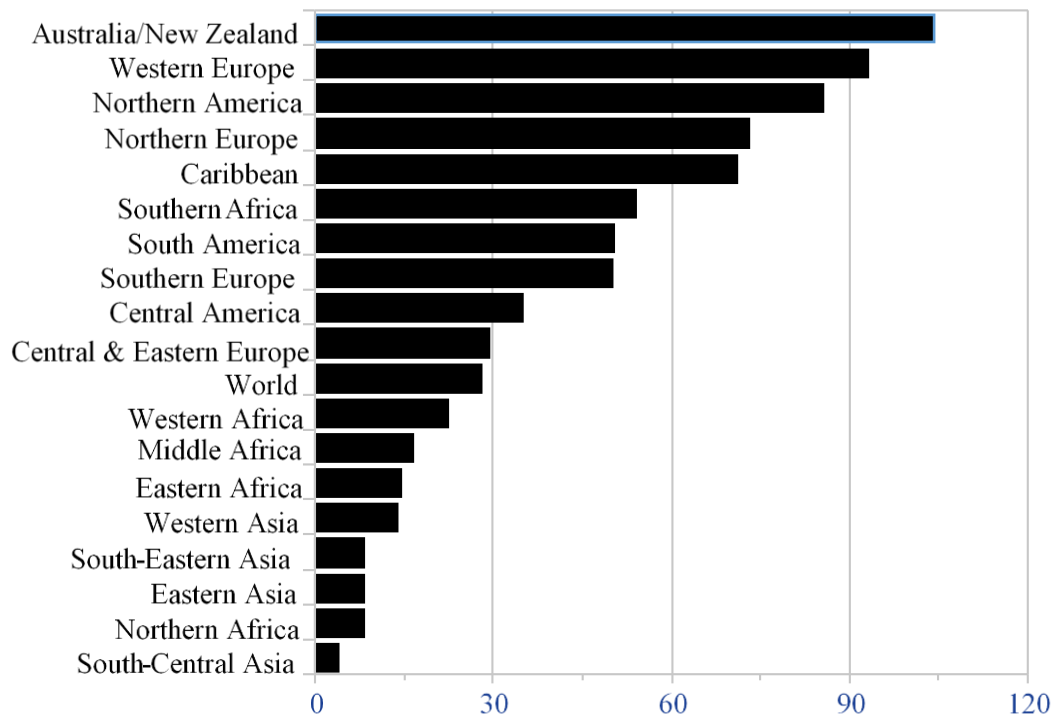


Figure 1. World age-adjusted prostate cancer standardized incidence rates. Adapted from Cancer Research U.K. Original data sources: International Agency for Research on Cancer (IARC). (2010). GLOBOCAN 2008. Retrieved from <http://globocan.iarc.fr>.

The lower incidence rates reported for countries in Africa have been described by some researchers as possibly due to under-diagnosis, under-reporting, lack of screening, a relatively shorter life span, and possibly a lower prevalence of risk factors (Hsing & Devesa, 2001)

Mortality rates have fallen in the United States and Canada as well as in several other countries such as Finland, Sweden, Portugal, Israel, Italy, the Netherlands, Norway and France (Baade et al., 2009). The reasons for this decrease are not clear, but Baade et

al. theorized that improved treatment and early detection may be important factors. It is interesting to note that in spite of data showing the highest incidence of prostate cancer in the United States and in men of African descent, the highest mortality rates have been reported in Scandinavian countries such as Norway with 28.4 per 100,000; Sweden with 27.7; and Iceland with 23 per 100,000. These are compared to the U.S. mortality rate of 15.8 per 100,000 (Haas, Delongchamps, Brawley, Wang, & de La Roza, 2008).

Zeigler-Johnson et al. (2008) found contradictory evidence that mortality rates are highest in populations of African descent. Data from the World Health Data Mortality Bank (as cited by Muir, Nectoux, & Staszewski, 1991) of age-adjusted mortality rates from 1972-1977 seemed to validate Zeigler-Johnson's findings. The Caribbean countries of St. Vincent/Grenadines, Martinique, and Bermuda were identified as having the highest prostate cancer mortality rates of 29.1, 28.6, and 28.3 per 100,000 respectively (Angwafo, 1998).

The differing incidence and mortality data are confusing and adds to the uncertainty of what the true comparative incidence and mortality rates are amongst different races and ethnicities, between countries, and worldwide. Sridhar, Masho, Adera, Ramakrishnan, and Roberts (2010) conducted a meta-analysis and concluded that there were no differences in prostate cancer specific or overall survival rates between American Blacks versus Whites after accounting for methodological flaws in several of the studies.

The effect of migration from areas of low- to high risk areas has also been evident in several studies. For example, the prostate cancer risk of Asian-American first-

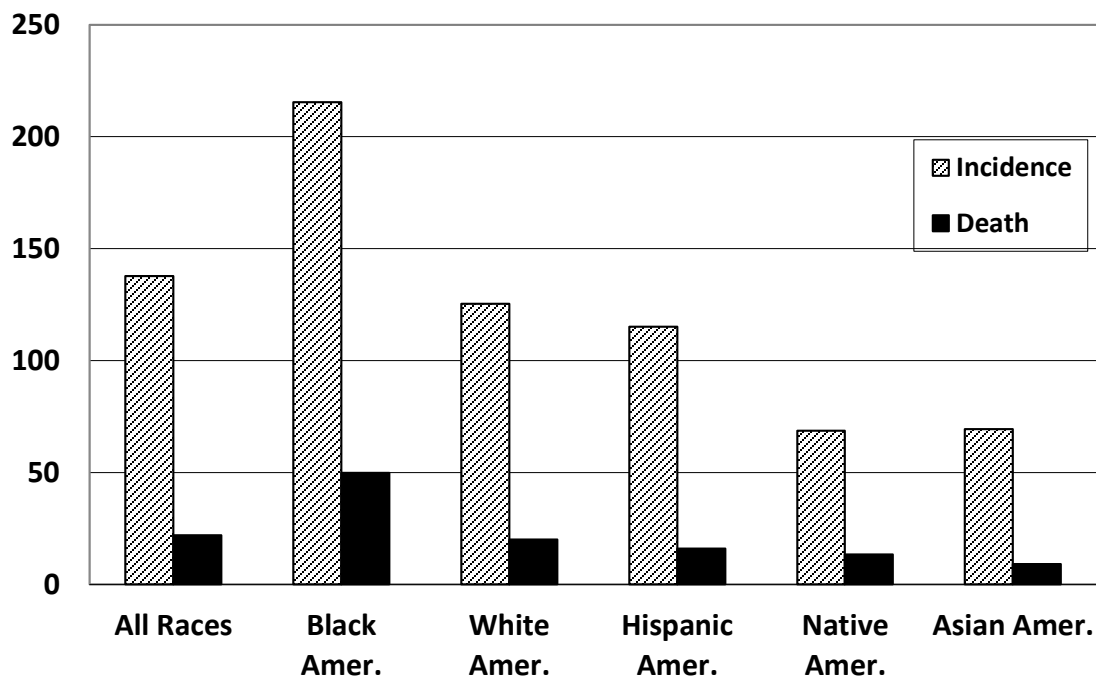
generation immigrants born outside the United States is similar to that of Asians residing in Asia (Cook, Goldoft, Schwartz, & Weiss, 1999). However, there was an increase in the incidence rate for Japanese residing in the United States, suggesting the importance of exogenous factors such as diet interacting with genetic, epigenetic, and environmental influences, and may be partly responsible for ethnic variations in the progression of prostate cancer (Watanabe, Nakayama, Shiraishi, Stemmermann, & Yatani 2000).

Dynamics of Prostate Cancer in African-American Men

Jemal et al. (2010) as well as several other researchers noted that African-American men have the highest incidence of prostate cancer worldwide, are more likely to develop prostate cancer at any age, and develop the disease earlier in life than men from all other racial and ethnic groups. Based on the U.S. Cancer Statistics (U.N.C.S) from the Center for Disease Control and Prevention (CDC) for 2009, the age adjusted incidence rate for African-American men was 215.5 per 100,000 (Siegel et al., 2013).

As shown in Figure 2, the age-adjusted African-American incidence rate of 215.5 is compared to the age adjusted rates per 100,000 for American men of all races at 137.7, White American men at 125.5, Hispanics at 115.2, Asians at 69.3, and Alaska Native/Native Americans at 68.7 (ACS, 2013; Siegel et al., 2013). As Figure 2 also shows, in 2009, the age adjusted death rate for African-American men was 50.0 per 100,000. The African-American age adjusted death rate is compared to the per 100,000 age adjusted death rates for all American men at 22.0, White American men at 20.2, Hispanics at 16.1, Asians at 9.2, and Alaska Native/Native Americans at 13.5 (ACS, 2013; Siegel et al., 2013).

Figure 2. Prostate cancer incidence and death rates in America. (Based on data from the United States Cancer Statistics from the Center for Disease Control and Prevention



(CDC) for 2009. (ACS, 2013; Siegel et al., 2013).

Prostate Cancer Information and African-American Males

To make informed decisions on how to detect the onset or development of prostate cancer at an early stage, it is imperative that all men, particularly those at high risk such as African-American males, receive or have access to information on risk factors, screening and early detection testing, and potential advantages and disadvantages of participating in such programs.

The ACS recommends that all men should be provided enough information to help them make early diagnostic and preventative decisions (ACS 2013). However, Ross et al. (2011) noted that as many as 49% of African-Americans males reported that they never received information on prostate cancer. The North Carolina study conducted by

Demark-Wahnefried, Strigo, Catoe, Conaway, Brunetti, and Rimer (1995) also showed that only 28% of Black men reported that their physician ever discussed testing for the disease.

Awareness of Prostate Cancer among African American Men

In a study by Allen, Kennedy, Wilson-Glover, and Gilligan (2007), the authors found that awareness of the disease and its risk factors, the location and function of the prostate, and the role of screening, was minimal among African-American participants. According to the Allen et al. study, few participants knew that African-American men were at increased risk, and they expressed frustration because they perceived it as difficult to get information on the disease, particularly from their medical provider (Allen et al., 2007). Demark-Wahnefried et al. (1995) found that a large number of these men were not aware that race or heredity are risk factors. Clarke-Tasker and Wade (2002) reported that older African-American men were more informed about prostate cancer because they were experiencing symptoms, whereas younger men in the same group knew little or nothing about the disease.

How African-American acquire prostate cancer information. Ross et al. (2011) noted that there is considerable variability in how African-American men acquire information on prostate cancer prevention and control. The most common sources provided were physicians, mass media, and printed sources, with information from the internet and peers as the least popular sources (Thompson, Cavazos-Rehg, Tate, & Gaier, 2008). However, many African-American men generally do not have an ongoing relationship with a primary care physician, and contact is more likely to be a consequence

of a late-stage cancer diagnosis. This was supported by the fact that most calls to the Cancer Information Service (CIS) by African-American men were related to coping with the disease rather than seeking preventative information (Thompson et al., 2008).

Demark-Wahnefried et al. (1995) also found that African-American males were less likely to report knowing someone with prostate cancer, did not believe that men with prostate cancer can lead normal lives, or that men can be symptom-free but yet have prostate cancer.

Early Detection in African-American Men

Whatever screening modality is used, there is evidence of both benefits and harms from these early detection procedures. The American Cancer Society (2013) reported that although screening tests are able to detect early-stage prostate cancer, it is unclear if subsequent treatment actually leads to a change in the outcome of the disease. In addition, there is evidence that early detection of prostate cancers that would not have caused clinical problems leads to overtreatment, and may result in unnecessary side effects such as erectile dysfunction, urinary problems, and adverse psychological issues in men who have had a biopsy but did not have prostate cancer (Merrill et al., 1996).

African-Americans, DRE and PSA testing. Although African-American men have been shown to have the highest incidence and mortality rates for prostate cancer, this group is less likely to undergo screening and other early diagnostic and preventative procedures such as PSA testing and DREs (Oliver, 2007). In a survey of African-American men, 51% stated that their physician advised them to get a PSA test and 60% said they had been tested (Steele, Miller, Maylahn, Uhler, & Baker, 2000). Steele et al.

also noted that men who received advice to get a PSA test were 28.5 times as likely to report being screened than men who did not received such advice. The number of Black men who reported having a PSA test in the Steel et al. study was significantly higher than in the North Carolina Study which found only 20% of Black men reported ever having a PSA test (Demark-Wahnefried et al., 1995).

Many African-American men have expressed concern and hesitancy over having a DRE performed on them. Clarke-Tasker and Wade (2002) noted that younger African-American men verbally expressed concern about having a DRE because they perceived it as degrading. Several men in the Clarke-Tasker and Wade study who had a DRE believed the physician used his entire hand rather than just one finger. However, most men in the study were not opposed to such an exam if it was presented as part of an overall physical examination (Clarke-Tasker & Wade, 2002).

Factor effecting testing in African American men. Forrester-Anderson (2005) reported that several researchers have suggested that deeply embedded beliefs, customs, experiences, and practices of African-American men may contribute to the lower level of screening in this group. Physician advice was found to be a significant determinant in screening behavior in the Steele et al. (2000) African-American Men Survey study. However, as many as 72% of all men in the North Carolina study noted that their physician had never discussed testing for prostate cancer with them (Demark-Wahnefried et al., 1995). Weinrich et al. (1998) reported that only 47% of African-American men who had participated in a prostate cancer educational program obtained a DRE and PSA

even after receiving a voucher for a free screening. That was compared to 71.9% of Caucasian males who chose to take advantage of the free screenings.

Barriers to screening. There are several factors that influence whether African-American men seek preventative strategies such as PSA testing or DRE examinations. However, the most significant variable that affected the odds of being screened was insurance coverage (Emerson, Reece, Levine, Hull, & Husaini, 2009). Significant increases in knowledge, perception of risk, modification of beliefs, and social support for screening were observed as support and validation of the HBM (Emerson et al., 2009). However, the authors also noted that having insurance coverage increased the odd of getting screened more than that of increased perceived risk, and as much as 14 times more than having increased knowledge (Emerson et al., 2009). Forrester-Anderson (2005) also reported that several researchers have suggested that deeply embedded beliefs, customs, experiences, and practices of African-American men may contribute to the lower level of screening in this group.

Specific barriers such as limited access to screening services; limited knowledge about the disease; embarrassment and fear of a positive diagnosis; distrust of medical and government professionals; reluctance to talk about sex-related health issues; and complacency about having the disease have made early detection, prevention, and treatment of prostate cancer very complex. Several of the barriers found by Forrester-Anderson (2005) were also noted by Allen et al. (2007), particularly relating to the misconceptions about the nature and pathology of the disease, minimal awareness of the

role of PSA, hesitancy to seek PSA testing, limited access to care, and general lack of information about preventative health.

Perceptions of Prostate Cancer amongst African-American Men

Several researchers have identified a number of perceptions relative to prostate cancer among African-American men. One study by Forrester-Anderson (2005) found that some African-American men believe that prostate cancer is a result of sexual activity (or lack of it), having multiple partners, processed food and diets high in fat and salt, being sexually overactive, and sexually transmitted diseases.

Parchment (2004) in a study of African-American and Caribbean men found that all the men in the research group had some knowledge of the effects of prostate cancer, but 75% of them were not referred to screening by their physician. The majority of men in the study also reported knowing of the dangers of delayed screening and 60% listed fear of impotence and incontinence associated with prostate cancer treatment. They also revealed that they disliked the idea of a digital rectal examination (Parchment, 2004).

It is important to note however, that the high percentage of study participants who had knowledge of prostate cancer and the dangers of delayed screening were surveyed after attending a seminar on prostate cancer. The high incidence of awareness in the Parchment study group may not paint a real picture of the true level of prostate cancer awareness among African-American men.

Few qualitative studies have focused on African-American males and their perceptions of prostate cancer, but results of those few studies have revealed several common themes. According to Sheldon et al. (as cited by Parchment, 2004), the most

frequently occurring themes were lack of knowledge of the disease; misconceptions about its cause; fear of the outcome if they get prostate cancer; misconceptions about their susceptibility; limited finances; lack of access to medical care and screening; lack of insurance; lack of knowledge about the benefits of screening; and expected discomfort associated with early detection methods.

In a study by Ferrante, Shaw, and Scott (2011) where 50 out of 64 participants were White, the authors found that reasons given for not being screened for prostate cancer were similar to those given by Blacks in other studies. Obstacles noted in the Ferrante et al. study were lack of knowledge, fear of cancer, embarrassment, and threats to manhood. Ferrante et al. noted that distrust of the medical system was not mentioned by the sample of predominantly White men in their study, but it was a major reason given by Blacks in several other studies.

Prostate Cancer and Native African Men

As evidenced by a wealth of data and discussed earlier in this document, the incidence of prostate cancer in African-American men is amongst the highest in the world. However, it is unclear if the incidence and mortality rates for African men residing in Africa or those that have migrated to other countries are similarly high. Based on estimates from the International Agency for Research on Cancer (IARC, 2010), prostate cancer is the leading cancer in terms of incidence and mortality in men from Africa and the Caribbean.

Prostate Cancer Incidence in African Countries

According to Haas and Sakr (1997), major unexplained differences exist in prostate cancer incidence even within the African continent. For example, in Zimbabwe, the age-standardized prostate cancer incidence rate per 100,000 is 32; 9.7 in Nigeria; 4.4 in Senegal; and 4.3 in Uganda. However, the incidence rates for South African Whites are similar to those of British men at approximately 32.6 per 100,000 and are therefore higher than those of black Africans in all of the countries mentioned (Haas & Sakr, 1997; Hill, Wynder, Garbaczewski, Garnes, & Walker, 1979).

Chu, Ritchey, Devesa, Quraishi, Zhang, and Hsing (2011) determined that rates among African-Americans were found to be as much as 40 times higher than those in Africa. The highest rates were found in East Africa with incidence rates of 10.7-38.1 per 100,000. Southern African Blacks had a rate of 14.3-21.8 per 100,000, and West African countries had the lowest rate of 4.7-19.8 per 100,000. As an example of the stark incidence differences between American Blacks and African men, The Gambia had an incidence rate of 4.7 during 1997-1998 versus an African-American rate of 80 to 195.3 during the same period (Chu et al., 2011).

Proposed reasons for differences in incidence. There is considerable debate on the reasons for the large incidence rate variations among Blacks living in Africa. However, several scholars such as Chu et al. (2011); Mohammed, Nwana, & Anjorin, 2005; and Odedina et al. (2009) speculated that differences in lifestyle, access to medical care, quality of the registries, and screening practices may contribute to the wide range of incidence in Black men living in Africa. For most of Africa, access to medical care is

limited and this may be a significant contributor to underdiagnosis. For example, Chu et al. posited that only four percent of Ghanaian men had access to medical care in 2004-2006 (unpublished data), compared to almost 80% of African-American males who had some sort of health coverage in 2008 (Chu et al., 2011).

Effect of immigration on incidence. African-Americans and other men of West African descent who reside in the Caribbean and Europe are seen to be connected through the transatlantic slave trade. Therefore, the higher incidence of prostate cancer in populations of African descent may be related to the common ancestry they share (Odedina et al., 2009). The variability in risk among African men living in different environments and cultures emphasizes the contribution of behavioral factors that may modify the biological risk factors (Odedina et al., 2009). Emigration and acculturation may effect changes in incidence rates and perceptions of prostate cancer for men who have relocated to different countries.

Odedina et al. (2009) found that Nigerian men who moved to the United States displayed cognitive-behavioral characteristics that are more representative of their new country. This phenomenon has been observed in other cultural and ethnic groups such as Chinese and Japanese immigrants that will be discussed later in this chapter. It may be prudent to suggest that while the incidence of prostate cancer in these groups may increase because of environment and dietary differences as shown in some studies, there may also be an increase in knowledge and attitudes towards prostate cancer screening as well as an increase in testing (Odedina et al., 2009).

Availability of incidence and mortality data. There is evidence that the prostate cancer incidence rate for Nigerian men as reported by the World Health Organization (WHO) may be underestimated because of lack of data on incidence and mortality in developing countries (Mohammed et al., 2005). This shortcoming may also be true for most developing countries (Odedina et al., 2009). Data on prostate cancer in Africa is very limited and therefore for comparative purposes, Chu et al. (2011) used cancer rates for African-Americans and American Caucasian men from the Surveillance, Epidemiology, and End Results (SEER) Program during 1973 to 2007 and examined trends during the same period for three African registries (SEER, 2011).

Quality of registries. The quality of the registries may be important as it relates to the disparities between different African countries. For example, The Gambia had the lowest incidence rate for prostate cancer, but the availability of pathology services was quite low, which possibly compromised the quality of cancer diagnoses. In The Gambia, Parkin, Whelan, Ferlay, and Storm (2005) found that only 20% of cases were morphologically verified in 1997-1998, compared to Harare, Zimbabwe which had the highest incidence rate with 63% of cases morphologically verified in 1998-2002 (Curado, Edwards, Shin, Storm, Ferlay, & Heanue et al., 2007). The morphological confirmation rate in both those countries was less than in the United States, where more than 93% of cancer cases have been histologically confirmed since 1973 (SEER, 2009).

Chu et al. (2011) contended that the documentation of cases based on death certificates would not include men with the disease who did not die, and may significantly underestimate the true incidence of prostate cancer in African countries.

Consequently, the true prostate cancer incidence is likely to be significantly higher than currently reported in native African men (Chu et al., 2011).

Early Detection in Native African Men

Prostate cancer incidence rates in Africa have increased between 1987 and 1992 and continue to increase over time (Chu et al., 2011). According to Rebbeck et al. (2013), no data exist on the prevalence of PSA testing in Africa, but it is generally held that early detection testing is not common. Given that PSA testing is relatively rare in most African countries, it is likely that improved availability and access to medical care and systems, as well as better attainment, reporting, and documentation of cases may contribute to the increasing incidence rates (Rebbeck et al., 2013).

While total prostate cancer rates are consistently higher in the United States than in Africa, advanced stage rates have been much higher in East Africa than those of African-Americans in recent years (Chu et al., 2011). That finding is not surprising given that prostate cancer is more likely to be diagnosed at an advanced stage because of the limited amount of screening done to detect the disease in its early stages. That presumption is supported by Chu et al. (2011) who noted that based on unpublished data, 75% of cases in Ghana and 47% of cases in Senegal were diagnosed at an advanced stage.

Based on the review and analysis of published studies and data, prostate cancer incidence in Africa has been shown to be lower than that of African American men. Total cancer rates in Africa are similar to advanced stage prostate cancer rates in the United States and those rates are projected to increase as early detection testing and clinical

diagnosis becomes better and the economies of the various countries improve. Chu et al. (2011) also postulated that increased PSA testing, the effect of increased westernization, particularly relating to changes in diet and lifestyle, will contribute to continued increases in the incidence rate of prostate cancer on the African continent in the future.

Prostate Cancer and Black men in the United Kingdom

Unlike African-American men whose historical pass and movement to the United States is tied to their history of slavery, Afro-Caribbean men have traditionally immigrated to the United Kingdom for employment in order to better provide for their families (Peach, 1968).

History and immigration patterns of Black men to the United Kingdom

Immigration to Britain from the Caribbean was driven by several different factors. Caribbean men who were recruited to assist in the Second World War, British Rail, London Transport, and the National Health Service played a significant role in the Black immigration movement to the United Kingdom (Peach, 1968). Unlike the initial movement of Blacks into the United States which was primarily a consequence of the slave trade, emigration of Caribbean Blacks to Britain was driven by free market labor economics (Peach, 1991).

Between 1950 and the early 1960s, the demand for Caribbean labor closely mirrored the demand for labor in Britain. Consequently, net immigration to the United Kingdom was inversely related to employment rates in Britain (Peach, 1968). Most of the initial emigrants from the English-speaking Caribbean to the United Kingdom starting in 1948 were from the islands of Barbados, Jamaica, and Trinidad. After 1960,

immigration increased from Guyana; Belize; the Leeward Islands of Martinique, St. Lucia, St. Vincent, the Grenadines, and Grenada; and the Windward Islands of Dominica, Montserrat, Antigua, Barbuda, St. Kitts, Nevis, the Virgin Islands, and Anguilla (Peach, 1968).

Peach (1991) noted that the size of the ethnic Caribbean population in Britain between 1971 and 1981 appeared to be stable at about 540,000. However, by 1988, that population had decreased significantly to 495,000. Peach (1991) speculated that the primary reason was due to some immigrants and their children returning to their native countries.

Prostate Cancer Incidence Rates in the United Kingdom

Over the last 30 years, prostate cancer rates in the United Kingdom have increased almost three-fold (Kheirandish & Chinegwundoh, 2011). However, the authors also noted that similar to the situation regarding research in Black men in the United States, few studies have focused on the risk and incidence of prostate cancer in Black men in the United Kingdom.

In a study entitled, “The risk of prostate cancer amongst Black men in the United Kingdom: The PROCESS cohort study,” the authors compared incidence rates of first-generation Black migrants from Africa and the Caribbean with those of Caucasian men in the United Kingdom (Ben-Shlomo et al., 2008). Black men in the PROCESS cohort study had an age-adjusted prostate cancer incidence rate of 173 per 100,000 compared to a rate of 56.4 per 100,000 for U.K. White males. Those rates were compared to the

SEER data of 1999 which showed an incidence rate for African-American men as 283 per 100,000, and 172 per 100,000 for U.S. White men (NCI, 2013).

In the PROCESS cohort study, it was determined that Afro-Caribbean men had the highest prostate cancer incidence rate in the United Kingdom, were three times more likely to be diagnosed with the disease, and were diagnosed approximately five years earlier than U.K. Caucasian men despite having equal access to diagnostic services. Black men were also more likely to be referred by an emergency department or other hospital team in the United Kingdom. That may suggest that initial suspicion of a prostate problem may have been related to presentation with symptoms. It further suggested that they may have been diagnosed at a later stage than in their White counterparts (Ben-Shlomo et al., 2008).

The National Cancer Intelligence Network (2006) reported that between 2002 and 2006, the cancer incidence for Blacks in the United Kingdom ranged from 120.8 to 247.9 per 100,000 compared to 28.7 to 60.6 per 100,000 for White U.K. men. Chinegwundoh et al. (2006) reported age-adjusted rates in the United Kingdom of 647 per 100,000 for Afro-Caribbean men; 213 for Europeans, and 199 for South Asians. It is unclear why there is such a stark difference in age-adjusted incidence rates between the Chinegwundoh et al. study and other prostate cancer studies of ethnic differences in the United Kingdom, but the three-fold relative risk for the Black population in their study was much higher than that found in African-American men.

Disparities in United Kingdom incidence rates. There are disparities in incidence rates from different studies conducted in the United Kingdom and disparities

also exist in the rates seen from studies of Black men in America, and Black men who reside in the Caribbean. Those disparities in incidence and mortality rates among the same ethnic populations in different countries may be partially accounted for by differences in the provision of urologic services, limitations regarding cancer registries, migration, and changes in social demography (Ben-Shlomo et al., 2008; Kheirandish & Chinegwundoh, 2011). However, consistent with studies conducted in the United States the data indicate that Black men in the United Kingdom are also at a significantly higher risk for developing prostate cancer compared to their White countrymen.

Prostate cancer clinical presentation in the United Kingdom. Kheirandish and Chinegwundoh (2011) concluded that Black men in the United Kingdom had a higher relative risk of developing prostate cancer than African-American men because of the lower rate found in White men in the United Kingdom relative to White men in the United States. Unlike data from several studies conducted in the United States, Chinegwundoh et al. (2006) found no difference in the clinical presentation of Black men in the United Kingdom versus White men. The authors theorized that the U.S. difference in clinical presentation may be because of limited access to health care and screening for African-Americans, while Black men in the United Kingdom have access to free health care.

Early Detection in Black Men in the United Kingdom Screening for prostate cancer is not recommended in England by the United Kingdom National Health Service and the National Screening Committee because of lack of evidence of its effectiveness relative to its risks (Gavin et al., 2004). However, men can be tested if they have read the

evidence-based information on PSA testing. Based on the Gavin et al. findings, almost 33% of men over 50 years of age have reported having at least one PSA test in the United Kingdom between 1994 and 1999. Unfortunately, there was not a breakdown by race or ethnicity in the Gavin et al. study, and available data on PSA testing and Black men in the United Kingdom have been difficult to locate.

Perceptions of Prostate Cancer amongst Black Men in the United Kingdom

One qualitative study conducted by Rajbabu, Chandrasekera, Zhu, Dezylyva, Grunfeld, and Muir et al. (2007) compared the knowledge and beliefs of African, Afro-Caribbean, and White men in the United Kingdom relative to prostate cancer. Similar to studies conducted in the United States, Rajbabu et al. (2007) found that even though Black men of African descent are at high risk of the disease, they had poorer knowledge of prostate cancer than White men did. This finding of lack of knowledge is consistent with qualitative studies of African-American men conducted in the United States by Allen et al. (2007); Clarke-Tasker and Wade (2002); Ross et al. (2011); and Thompson et al. (2008), as well as a literature review by Kleier (2003).

In the Nanton and Dale (2011) study of Afro-Caribbean men diagnosed with prostate cancer in the United Kingdom, slightly more than half of the participants perceived that Black men were twice as likely to die from prostate cancer as White men, but 16 of the 17 (94%) study participants had limited knowledge of the disease at the time of their diagnosis. Most of the men in the Nanton and Dale study did not recall getting any information on the disease, treatment, and side effects at the time of their diagnosis. The authors noted however, that the experiences of Afro-Caribbean men in the United

Kingdom reflected those of the majority of the population with respect to living with prostate cancer.

Prostate Cancer and Afro-Caribbean Men

History of Afro-Caribbean Migration to the United States

Although prostate cancer has been studied to a relatively large extent in African-American males, not many studies have focused on Afro-Caribbean men (Kleier, 2003). The association of African-Americans and Afro-Caribbean people has a long and historic past. Afro-Caribbean peoples and African-Americans were brought together when slaves from Barbados, many born in Africa, were taken by their British owners to South Carolina during the 17th century (Chamberlain, 2002). In the 18th century, people from the Caribbean outnumbered Africans brought there directly from Africa, and between 1715 and 1730, slaves from the Caribbean outnumbered African slaves by a ratio of three to one (Thomas, 2012).

Thomas also noted that voluntary migration of people from the British West Indies to the United States did not occur until around 1900, and between 1920 -1950, the number of Caribbean immigrants to the United States increased by more than 540%. From 1981 to 1990, approximately 1.2 million Caribbean peoples migrated to the United States. However, between 2006 and 2009, the overall number of Black immigrants from the Caribbean fell by about four percent, a possible consequence of the economic recession in the United States (Thomas, 2012).

Afro-Caribbean peoples are different from African-Americans and Africans in terms of cultural values, language, diet, customs, beliefs, and migration history. There

are also many cultural and other differences among Afro-Caribbean peoples that make classifying them as one homogenous group misleading. In the early part of the twentieth-century, Caribbean immigrants brought with them substantially higher levels of literacy, education, and skills than immigrants from Europe (Thomas (2012)).

Thomas (2012) also pointed out that immigrants from the English-speaking Caribbean after 1965 were disproportionately literate and skilled, with a large number being professionals or white-collar workers. However, that drastically changed between 2005 and 2009 when Black Caribbean immigrants were among the least educated immigrant groups in the United States. Thomas (2012) theorized that this change might be accounted for by more refugees from countries such as Haiti, and a greater proportion of immigrants coming from non-English-speaking Islands. In spite of the decline in average education levels, Caribbean blacks collectively earned higher median salaries than all immigrants to the United States between 2005 and 2009 (Thomas, 2012).

Prostate Cancer Incidence Rates and Afro-Caribbean Men

Very high prostate cancer incidence rates have been reported for men in the Caribbean region (Glover et al., 1998; Gibson et al., 2010; Bunker et al., 2006; Mallick, et al., 2005; Hennis et al., 2011). Despite the effect on men's health and mortality in the Caribbean region, information on prostate cancer incidence rates, risk factors, and public health implications for Afro-Caribbean men is sparse and inconclusive (Hennis et al., 2011). Qualitative data on how Afro-Caribbean men perceive the disease and their susceptibility to it is also lacking.

Jamaica. A prostate cancer incidence rate of 304 per 100,000 has been documented for Jamaicans by Glover et al. (1998). That rate represented one of the highest in the world. However, more recent data from Gibson et al. (2010) and Ben-Shlomo et al. (2008) disputed the accuracy of the Glover et al. rates. Gibson et al. reported that the Jamaican age-standardized rate (ASR) for prostate cancer for the period 2003 to 2007 was 78.1 per 100,000. The Jamaican incidence rates as documented by Gibson et al. (2010) showed an increase from 65.5 to 78.1 per 100,000 which are significantly below the rate of 304 per 100,000 that was reported by Glover et al. (1998).

The study by Ben-Shlomo et al. (2008) supported the revised data and estimated the corrected unadjusted incidence of prostate cancer in Jamaica to be 70 per 100,000. Gibson et al. (2010) noted that the age-standardized rates for prostate cancer in Jamaica continue to climb as PSA testing becomes more prevalent. Given the documented association of increase in reported incidence with increase in screening, it might be reasonable to assume that the documented incidence rates will also increase in other Caribbean islands.

Barbados, Trinidad and Tobago. Although the exceptionally high incidence rate of 304 per 100,000 found in Jamaican men has been disputed, disparate and confusing incidence rates have also been reported for Barbadian men (Hennis et al., 2011), and Afro-Caribbean men on the islands of Trinidad and Tobago (Bunker et al., 2006).

Hennis et al. (2011) found that the crude incidence rate in Barbados was 131.0 per 100,000 compared to 248.2 for African-American; 158.0 for White Americans; 163.1 for

European; and 112.0 for the World. For African-Americans age 40 - 44 years, the age-specific incidence rate was 22.9 per 100,000 versus 6.0 per 100,000 for Barbadian men of the same age, representing an almost four times lower incidence rate for Barbadians. Those findings seem to indicate that the crude incidence rate for Black Barbadians is lower than the rate for African-Americans, and even for Caucasian-Americans.

The overall mortality rate from probable and definite prostate cancer in Barbadian men between 1995 and 2008 ranged from 63.2 to 101.6 compared to 51.1 to 78.8 per 100,000 for the same time period for African-American men (Hennis et al., 2011). Hennis et al. (2011) posited that the similar prostate cancer mortality rates seen in Barbadian and African-American men should be a cause for concern given the lower incidence rate in Barbadian men compared to African-American men.

Martinique and Guadeloupe. Researchers of Afro-Caribbean men on the islands of Martinique, and Guadeloupe have found the prostate cancer incidence to be amongst the highest in the world. Those incidence rates were 152.3 per 100,000 as noted by Mallick et al. (2005) and 173.7 per 100,000 as documented by Belpomme & Irigaray (2011). Guadeloupe and Martinique have a similar geographic location, French association, and access to health care.

Environmental effect and Martinique and Guadeloupe rates. Belpomme and Irigaray (2011) found that although the incidence rate in Martinique has been growing continuously since 1985 at a rate similar to that of metropolitan France, it remains consistently higher at 173.7 per 100,000 than that of men in metropolitan France whose rate is 118.3 per 100,000. Belpomme and Irigaray (2011) asserted that because the health

care system and access to testing techniques in Martinique are almost the same as in France, it is unlikely that the higher incidence rates may be due to a difference in screening.

According to Belpomme and Irigaray, given the similarities in the health care systems and the difference in the local environments between France and the islands of Martinique and Guadeloupe, a strong interaction between genetic and environmental factors may be involved in the difference in incidences between France and the two Caribbean (Belpomme & Irigaray, 2011). This association has been shown consistently in people from the same ethnicities such as Japan and China who now live in different geographic areas under different environmental conditions and show different incidences in prostate cancer than their native countries (Angwafo, 1998).

Qualitative Studies of Prostate Cancer and Afro-Caribbean Men

Apart from the Kleier (2004) study, very few qualitative studies have been done on Afro-Caribbean men and prostate cancer. At the time of the Kleier study, the author noted that there was only one other study entitled “The New York Task Force on Immigrant Health” (as cited by Kleier, 2004) that looked at the beliefs and health care seeking behavior of Afro-Caribbean immigrants residing in the United States relative to cancer. That study had several short-comings that limited its applicability to prostate cancer and Afro-Caribbean men. First, only three of 13 (28%) participants in one focus group were men, only six of 13 were over 40 years of age (46.2%), and race was not reported. In another focus group of the New York Task Force study, only two of 20 (12.5%) were over the age of 40, and neither race nor gender was reported (Kleier, 2004).

The findings from such a study therefore offer limited insight into the perception, experiences, attitudes, and knowledge of Afro-Caribbean men relative to prostate cancer.

The Kleier (2004) study focused on the perceptions of Jamaicans and Haitians to prostate cancer, and although it gives some insights into attitudes of men from those islands, a sample of men from two islands does not provide a broad enough spectrum to be representative of how Afro-Caribbean men may perceive the disease. That is not a criticism of the study because the author never asserted that it was a study of Afro-Caribbean men, and as she pointed out, it highlighted the difficulty of getting a broad enough sample of men from enough Caribbean islands that could provide better insight into their views on prostate cancer.

One possible shortcoming of the Kleier (2004) study however, is that the life expectancy of men living in Haiti was 45 years at the time of the study, and although the World Health Organization reported that the life expectancy of Haitian men is 61 years, many Haitian men may die before the disease manifests itself in that group (WHO, 2011). The Kleier (2004) findings also demonstrated that language and cultural differences are important factors in how men view the disease, as those factors appear to have a negative impact on level of prostate cancer knowledge and their perception of the severity and potential outcomes.

In their study of prostate cancer incidence and mortality in Barbados, Hennis et al. (2011) noted that unlike in the United States where socioeconomic and health care access issues need to be taken into account when investigating prostate cancer and African-American men, Barbados provides free and equal access to comprehensive healthcare.

The population of Barbados is approximately 95% Black and fewer than five percent White.

The prostate cancer incidence rate for Black Barbadian men was similar to that of White Americans between July 2002 and December 2008 at 160.4 per 100,000. The incidence rate for African-Americans for the same period was approximately one and a half times higher (Hennis et al., 2011). However, while overall mortality rates for African-American men declined between 2000 and 2006, the mortality rate for Black Barbadian men increased during the same period.

Early Detection in Afro-Caribbean Men

One study of Afro-Caribbean men living in Tobago by Bunker et al. (2002) suggested that the PSA screening rate for that small island might be twice the rate seen in African-Americans. When compared to the data from a study by Richie et al. (1993), the prostate cancer prevalence detected by screening in the Bunker et al. study was three to four times higher than seen in screening studies of White men. Bunker et al. (2002) theorized that the high Tobago prevalence rate may have been associated with the high biopsy rate of 90% seen in the study of Tobago men, compared with 69% in the Richie et al. (1993) U.S. study. It is important to note that the number of men recruited in the Tobago study was 80% of the total population of men on the island.

Although specific data on the percentage of Afro-Caribbean men that undergo PSA and/or DRE screening is lacking, it is highly unlikely that such a high screening percentage recorded in the Tobago study is prevalent in other islands or amongst Afro-Caribbean men in other geographic locations. One of the reasons that incidence rates

may be higher than reported in the Afro-Caribbean population is because screening for prostate cancer is not prevalent amongst that group. However, Bunker et al. (2002) also reported a 10% prevalence for prostate cancer detected by screening, which may suggest a potential impact of screening on prostate cancer rates (Hennis et al., 2011).

In a study of Afro-Caribbean and African-American men by Parchment (2004), 80% of participants stated that some of the main reasons why they avoided early detection test for prostate cancer were dislike of the DRE and the perception that prostate cancer can cause impotence and incontinence. Seventy five percent of the men in the Parchment study stated that information provided by their physicians did not cause them to seek regular screenings. Lee et al. (2012) evaluated the association between the barriers to healthcare access and PSA screening among African-American and Afro-Caribbean men and determined that men who had difficulty accessing quality care or found the health care system as inconvenient were less likely to have a PSA test.

Perceptions of Prostate Cancer amongst Afro-Caribbean Men

Kleier (2004) in her study of Jamaican and Haitian men found that most Jamaican men were aware of the signs and symptoms, knew of the risk factors for prostate cancer, and most reported being tested in the last five years. However, there was less agreement on the severity of the disease. In the Haitian cohort of the Kleier study, men were less aware of the signs and symptoms, and many believed that prostate cancer was associated with sexual function and sexual indiscretion. Haitian men also believed that once you had prostate cancer, the chance of survival was small.

Magnus (2004) found that prostate cancer knowledge seemed adequate among multi-ethnic Black men in Miami and Fort Lauderdale, Florida. However, prostate cancer knowledge was not significantly different based on ethnic groups, and it was significantly lower for men who had no history of prostate cancer or were in the lower-income range (Magnus, 2004). Magnus also noted that perceived knowledge of prostate cancer was positively correlated with level of education, family history of prostate cancer, and income level.

Kleier (2003) posited that based on her review of the literature on prostate cancer in Black men of Afro-Caribbean descent, there is a general lack of knowledge of prostate cancer. Most Afro-Caribbean participants in the studies reviewed by Kleier also had misconceptions of the causes of the disease, did not participate in early detection programs, and when they experienced symptoms, they either did not understand the significance of those symptoms, or were reluctant to seek medical evaluation.

Pedersen, Armes, and Rearn (2012) conducted a literature review entitled “Perceptions of prostate cancer in Black African and Black Caribbean men: A systematic review of the literature.” The authors included 33 different studies that were expected to address the article topic. However, none of the conclusions from this literature review made any specific reference or findings that were specific to the population they were reviewing. Only two of the 33 studies reviewed included African men as study participants; only one reviewed article included Afro-Caribbean men; and one article studied black men in the United Kingdom who were either Afro-Caribbean, African, or

Blacks of unknown origin. The remaining 29 studies were of either African-American men or White American men, with one study that also included women.

The discussion section of the Pedersen et al. (2012) article contained general information about prostate cancer and Black men in general, and therefore this article contributes very little to the body of data on prostate cancer and Afro-Caribbean men. However, it highlighted the fact that there is a large gap in the data specific to Afro-Caribbean men and prostate cancer, and emphasized the need for the type of research that is contained in this paper.

Prostate Cancer and Other Races and Ethnicities

In contrast to the declining incidence of prostate cancer in Western countries, some Asian countries such as Japan where PSA testing is not often used are seeing increasing rates (Baade et al, 2009). Baade et al. postulated that westernization, including consumption of animal fat, increased obesity, and reduced physical activity may be possible factors. According to Angwafo (1998), the highest prostate cancer incidence rates in descending order are: North America, Northern Europe, Israel, Southern Europe, Latin America, and Asia. However, although the incidence rate in people of African descent, including men in and from Africa and the Caribbean region, are not in the Angwafo list, there is a wealth of evidence that has already been discussed in this chapter that demonstrate that those ethnicities are within the highest recorded incidences.

Muir et al. (1991) posited that the highest incidence rates in Europe are found in the Scandinavian countries of Sweden with a rate of 45.9, followed by Norway at 42.0,

and Switzerland at 45.8 to 50.1 per 100,000. Rates similar to those in Scandinavia have been reported in Canada, Newfoundland, and New Zealand. The lowest rates have been reported in the populations of Asia, but there is a contrast between the rates seen in Chinese residing in Shanghai at 1.8, those in Los Angeles at 16.9, and those in Hawaii at 25.2 per 100,000 (Muir et al., 1991).

Muir et al. (1991) also contended that a similar and notable type of difference has been observed in Japanese populations residing in Japan at 5.1 to 6.3, Japanese living in Los Angeles at 22.8, and Hawaii at 31.2 per 100,000. These data trends were similarly reported by Angwafo (1998) who noted that the incidence rates for Japanese men born in Brazil were twice those of men in Japan. The rates of Chinese men born in China but have lived in the United States for more than 25 years were three times higher than for those who lived in the United States for less than 25 years (Angwafo, 1998).

Based on several studies, Angwafo (1998) concluded that the geographic variations in prostate cancer incidence of the same ethnic groups living in different areas of the world, as well as those who have migrated to western countries such as the United States, seem to suggest that geography and environmental factors play a significant part as risk factors for prostate cancer. Hill et al. (1979) stated that results from epidemiological and migrant-study research have suggested that environmental factors of a possible dietary and lifestyle-change nature may be associated with prostate cancer. Breslow (as cited by Hill et al., 1979) postulated that those factors “may activate small latent lesions which occur at a constant frequency in all geographic areas, but which appear to progress to active lesions mainly in Western societies.”

Literature Review Related to Research Methodology

This study was designed to explore the health beliefs of a group of men presumed to be at significant risk of having and dying from the potentially fatal disease of prostate cancer. In considering an appropriate research methodology for this study, several factors were taken into account. The object of qualitative research is to focus on the human aspect of behavior in context. In this case, to seek to understand how the experiences, beliefs, and perceptions of Afro-Caribbean men may be affected by factors such as their level of understanding of the disease, how they acquire information, their perception of the importance of symptoms, preventative testing and early diagnosis, and the possible role of culture in their health beliefs. In-depth inquiries of those factors were important in answering the research questions, and the method of research chosen was critical in acquiring that information.

Qualitative Designs

Grounded theory. This is a form of enquiry that focuses initially on unraveling the elements of experience and seeks to develop a theory based on the study of those elements and interrelationships (Moustakas, 1994). Its primary focus is on generating theory rather than investigating the rich details of participants' lived experiences, beliefs, and perceptions that I was seeking in this study.

Ethnography. Ethnographic research assumes that any human group that interacts together for a period of time will evolve into a culture and the primary method of conducting such research is participant observation (Patton, 2002). According to Creswell (2008), ethnography is a form of enquiry where the researcher studies an intact

group in its natural setting over a prolonged period of time. Although the cultural component was deemed to be an important one in this study, demographic and other components that are necessary to such an approach were not present in this study group.

Case studies. A case study approach focuses on gathering in-depth, comprehensive data on one or more individuals (Patton, 2002). According to Creswell (2008), three variations of case study types exist in terms of intent. In the single instrumental case study, the research is focused on an issue or concern and then uses one bounded case to illustrate the issue. In a collective case study, a researcher selects multiple case studies to illustrate the issue. For an intrinsic case study, the focus is on the case itself such as evaluating a program (Creswell, 2008). For this study, I considered a multiple instrumental case study approach but determined that it would not provide the breadth of experiences and perceptions that were necessary.

Narrative research. Creswell (2008) defined narrative research as a specific type of qualitative design in which narrative is understood as a spoken or written text that gives an account of an event or action that is chronologically connected. One of the major challenges of using this approach is that a researcher needs to discuss the participant's stories while being reflective about their own personal and political background which can affect how they retell the story (Creswell, 2008). Similar to the case study approach, I determined that this design would not be adequate for this study.

Phenomenological research. The phenomenological approach is ideal when one needs to understand the common and shared experiences of a phenomenon, but is also useful in several other ways (Patton, 2002). It not only provides a description of

experiences and perceptions, it also facilitates an interactive process where the researcher can interpret the meaning of the lived experiences (Creswell, 2008, 2012). Creswell (2012) posited that in-depth interviews are the primary data-collection method used in phenomenological studies. A phenomenological research method was chosen for this study because it facilitated the exploration of the phenomenon of prostate cancer as it relates to the disease, the meaning of the disease to study participants, and how it affects or may affect their lives (Creswell, 2012).

Categories of phenomenological research. Moustakas (1994) categorized phenomenological inquiry into empirical or hermeneutic approaches. Descriptive phenomenology is intended to describe the general characteristics of a phenomenon, as well as to determine the meaning of the phenomenon (Giorgi 2008). Hermeneutics involve a focus on consciousness and experiences and contains both descriptive and interpretive aspects. The goal of hermeneutics is to describe, understand, and interpret participants' experiences (Tuohy et al., 2013).

Hermeneutic phenomenology. Hermeneutic phenomenology focuses on the consciousness and experience of study participants. According to Gadamer (as cited by Moustakas, 1994), in hermeneutic analysis, there are no moral phenomena, only moral interpretations of the phenomena. In the hermeneutic process, prejudgments are corrected based on the content of the text, and the understanding of that text leads to new prejudgments. Reflective interpretation of interview data is necessary to gain a fuller, more meaningful understanding (Moustakas, 1994). The reflective-interpretative process includes not only the description of the conscious experience, but an analysis and

interpretation of the historical and aesthetic conditions that influence the experiences and perceptions (Moustakas, 1994).

Examples of studies using the phenomenological approach. In my review of similar studies that used a phenomenological approach, one study by Sale (2006) examined the experience of participatory research on the perceptions of oncology employees participating in a workplace study. Sale used a sample of 15 participants and collected data through semi-structured face-to-face interviews. Interviews were videotaped and downloaded in NVivo. Only 12 participants participated and although there was no specific mention of data saturation, Sole noted that the sample size of 12 was consistent for the phenomenological approach (Creswell, 2008).

In a study by Akyüz, Güvenç, Üstünsöz, and Kaya (2008), the researchers used a descriptive phenomenological approach to investigate the essence of the experiences of women and their partners who had gynecological cancer. Participants were recruited until the data saturation limit was reached. In this particular study, 19 patients and 12 husbands were interviewed.

Although data saturation was determined to be reached in the Akyüz et al. study, other phenomenological studies had reached data saturation with fewer participants. For example, in a study by Guest, Bunce, and Johnson (2006), data saturation had occurred by the time they had analyzed twelve interviews. Data was collected in the Akyüz et al. (2008) study through a semi-structured interview process using open-ended questions. Interviews lasting 35-45 minutes were audio-recorded and transcribed. To maintain the credibility of data analysis, each researcher examined the transcripts independently to

identify the major categories of the transcripts. The coding was compared and differences were discussed until a final agreement was reached.

One other study by Mercer (2007) entitled, “Role transition and the nurse practitioner: An investigation into the experience of professional autonomy” was conducted using a phenomenological hermeneutic approach. Mercer interviewed 14 nurses using an open-ended format and the data were recorded and transcribed to create a series of texts for subsequent analysis. Data were analyzed using the help of a software program, and according to Mercer, a comprehensive understanding of the meaning of the phenomenon under review was formulated.

Reasons for Using Open-ended Interviews.

Patton (2002) noted that there are four main reasons for using the standardized open-ended interview, three of which were applicable to this study. First, the exact instrument used will be available if someone wants to look closely at the findings. Second, participants’ times will be used more efficiently as the interview will be more focused. Third, responses will be relatively easy to find making analysis somewhat easier. The primary purpose of the interview data-gathering process was to capture how participants view their world relative to prostate cancer, learn their terminology and judgments, and record their individual experiences, perceptions and beliefs relating to the disease (Patton, 2002).

In addition to open-ended questions, Moustakas (1994) suggested that participants should be asked at least two broad general questions that may lead to a broader description and understanding of their common experiences. He postulated that

interviewees should be asked questions such as “what have they experienced in terms of the phenomenon?” and “what situations have influenced their experiences of the phenomenon?”

Data Saturation and Phenomenology.

The concept of data saturation is an important one in phenomenology, but Mason (2010) noted that the point of saturation is difficult to identify and determine. In a study by Guest et al. (2006), the authors posited that data saturation had essentially occurred by the time they had analyzed twelve interviews. After twelve interviews, they found that they had created 92% of the total number of codes developed for all transcripts in their study (Guest et al., 2006). Data saturation will be discussed in greater detail in Chapter 3 of the proposal.

Summary

The focus of this literature review was on prostate cancer in Afro-Caribbean men, but it included studies of prostate cancer in men worldwide regardless of race, ethnicity, type of study, and geography. As the search evolved, several facts became evident very early in the process.

Conceptual framework. In a review of studies that utilized the HBM as a conceptual framework, critics noted that this model was validated only in North America and it would probably be limited in its application to a culturally and ethnically different population such as the participants in this study (Poss, 2001; Champion & Skinner, 2008). A synthesized model that incorporated the HBM and the TRA was used as the

supporting conceptual framework because the TRA allowed for a culturally based or culturally influenced study (Poss, 2001).

Limited information on the etiology and development of the disease. Review of the data on the etiology of prostate cancer indicated there are many unanswered questions about the causes of the disease. Researchers have differing views on why there are glaring differences in incidence and mortality rates based on race, ethnicity, geographic location, and in some cases, culture. In addition, the effect of environment is still a matter of debate. Several studies have found that cancer incidence rates among first-generation immigrants were almost identical to those of their native countries. However, those incidence patterns evolved over subsequent generations to resemble those of the countries to which they immigrated. Based on such data and other factors, Pienta and Esper (1993) postulated that risk factors other than increasing age may affect the development of the disease.

Limited and disparate incidence data on men of African descent. Apart from studies conducted on African-American men and Black men in the United Kingdom, there were very few studies available on prostate cancer on other men of African descent. Based on available data, there were many inconsistencies in the comparative incidence, mortality, and trend information of various studies for this racial group. Even though researchers generally agree that men of African descent are at a higher risk of having the disease, incidence rates among Black men who live in western, middle, and northern Africa were among the lowest in the world. Those rates were significantly lower than

rates for African-Americans and even Caucasian men in the North America, Australia, and Europe.

Disparities in **incidence rates** for the same **populations** based on **different studies**. Incidence rates were also found to differ for the same populations depending on which studies were reviewed. For example, one study by Glover et al. (1998) noted that the prostate cancer incidence rate for Jamaicans was 304 per 100,000, while two different studies reported the incidence in Jamaican men to be approximately 70 per 100,000 (Ben-Shlomo et al., 2008; Gibson et al., 2012). In addition, the range of age-adjusted incidence of prostate cancer in African-American men based on the available data was quite wide, ranging from 137 per 100,000 (Hsing et al., 2000) to over 215 per 100,000 based on CDC data (Frieden, 2013).

Theories for differences in incidence rates. Various assumptions and theories have been given for the differences that are documented in various studies. Lack of early detection screening, differences in access to health care, lack of educational, promotional, and preventative strategies, and a number of other apparently logical reasons have been provided. However, it is apparent that studies and available data that address many of those important questions are lacking, including the fact that many ethnic groups such as African-American and Afro-Caribbean men are disproportionately underrepresented in most prostate cancer studies. Researchers and clinician even disagree on what the true risk factors for prostate cancer are, and the definite effect of diet, socioeconomic factors, hormones, genetics, sexual behavior, and many other suggested risk factors remain unresolved.

Theories on why incidence rates are changing in the United Kingdom, North America, and Africa. In the review of global patterns of prostate cancer, it was interesting to note that while incidence rates are declining in North America, incidence rates in the United Kingdom and several the European countries have been increasing. Those trends have been attributed to the increase in PSA testing in Europe and declining use in the United States. It has also been strongly suggested that the rates in Africa and the Caribbean will increase as early detection practices are used more often, despite the continuing debate on the efficacy of the PSA test.

Lack of qualitative data on men of African descent. One of the more glaring findings was the lack of qualitative data on Black men and their perceptions of prostate cancer. Most of the few qualitative studies conducted on Black men have been on African-American men and Black men residing in the United Kingdom. However, the themes seem to be consistent as to how those men relate to the disease, testing, and therapy. Forrester-Anderson (2005) and Allen et al. (2007) found that deeply embedded beliefs, customs, experiences, limited access to screening services, limited knowledge about the disease, embarrassment and fear of a positive diagnosis, distrust of medical and government professionals, and reluctance to talk about sex-related health issues were all similar issues provided by Black men. It was interesting to find that several of U.S. Caucasian men's perceptions of prostate cancer and barriers to testing were similar those of African-American men. In a study by Ferrante et al. (2011) in which 50 out of 64 participants were White, the authors reported that reasons given for not getting screened for prostate cancer were similar to those given by Blacks in other studies. However,

distrust of the medical system was not mentioned in that sample of predominantly White men, but it was a major reason given by Blacks in several studies (Ferrante et al., 2011).

Lack of studies on Afro-Caribbean men. Very high prostate cancer incidence rates have been reported for men in the Caribbean region (Glover et al., 1998; Gibson et al., 2010; Bunker et al., 2006; Mallick, et al., 2005; Hennis et al., 2011). Despite the effect on men's health and mortality in the Caribbean region, information on prostate cancer incidence rates, risk factors, and public health implications for Afro-Caribbean men is sparse and inconclusive (Hennis et al., 2011). Qualitative data on how Afro-Caribbean men perceive the disease and their susceptibility to it is minimal. Of the few studies that are available, the percentage of participants from the Caribbean is either quite small (Pedersen et al., 2012), or the number of Caribbean countries represented is limited to two or three countries (Kleier, 2004).

Conclusion

Based on a comprehensive review of the literature on prostate cancer in Afro-Caribbean men and Black men in general, it is evident that there is a need for research in many areas relative to prostate cancer in Black men. Comparative data on incidence and mortality are inconsistent and confusing, and data on perceptions of the disease among Afro-Caribbean men are almost non-existent. Regardless of how Afro-Caribbean men compare to the rest of the world in terms of incidence, morbidity, and mortality from prostate cancer, studies such as those by Kleier (2003, 2004) argued that awareness needs to be raised and educational efforts need to be targeted to the Afro-Caribbean community. Based on this literature review, the evidence is clear that there is a lack of awareness and

a paucity of information on Afro-Caribbean men, a group that has been shown to be at high-risk based on data from available studies.

This study is aimed at addressing the gap in the literature by capturing how a cross-section of Afro-Caribbean men perceive prostate cancer-related issues such as their susceptibility and risk, early detection testing, benefits and risks from such testing, and how they get their prostate information. This study is the first of its kind in the United States that targets men from as many as seven English-speaking Caribbean islands and presents a broader representation the experiences, perceptions, and beliefs about prostate cancer.

Transition Statement

In Chapter 2, I focused on the literature search of prostate cancer with emphasis on Afro-Caribbean men. I also reviewed and critically assessed prostate cancer studies of African-Americans, Black men in the United Kingdom, studies of native Africans, and studies involving men from Europe and Asia. Most of the studies provided comparative incidence and mortality data, but the perceptions of participants in all those studies were also important to addressing the research questions in this paper.

In Chapter 3, I describe the research design and rationale, and the role of the researcher. I elaborate on the research methodology, which will include the instrument, procedures for recruitment, participation, and data collection. I also describe a data analysis plan, and finally, I describe in detail any ethical issues and procedures that are pertinent to this study.

Chapter 3: Research Method

Introduction

The purpose of this qualitative, phenomenological study was to explore and analyze the experiences, perceptions, and beliefs about prostate cancer in a sample of Afro-Caribbean men between the ages of 40 and 75 years old who reside in the United States. Belpomme and Irigaray (2011), Glover et al. (1998), and Mallick et al. (2005) all reported that the incidence of prostate cancer in Afro-Caribbean men is amongst the highest in the world. However, those studies were limited to men living in Martinique, Guadeloupe, and Jamaica, and most of the studies on Black men and prostate cancer in the United States have been conducted using African-American men as participants. In this study, I explored the experiences, perceptions, and beliefs of Afro-Caribbean men residing in the United States given that these men may have different views and perceptions of prostate cancer than African-American or Afro-Caribbean men living in the Caribbean or the United Kingdom.

Moustakas (1994) emphasized that in preparing to conduct a phenomenological study, the researcher must conduct an extensive review of the professional and research literature associated with the topic and questions. As demonstrated in the review of the literature and highlighted in Chapter 2, there is a paucity of information on prostate cancer and Afro-Caribbean men. In an attempt to address the existing gap in the data, I explored the experiences, perceptions, and beliefs about prostate cancer in Afro-Caribbean men and how the disease may affect them.

According to Patton (2002), the only way for a researcher to really know what another person experiences is to investigate the phenomenon as directly as possible through the important tools of in-depth interviews and/or participant observation. Given that it is not possible to observe feelings and thoughts, I chose to employ a series of standardized, in-depth, open-ended interviews to gather the stories of Afro-Caribbean men as well as to explore commonalities in their experiences, perceptions, and beliefs relative to prostate cancer (Patton, 2002).

In a critical review and analysis of the literature in Chapter 2, I discussed and demonstrated that the incidence of prostate cancer is higher and the disease pronounces itself at an earlier age in men of African descent than in men of other races. Several studies have shown that Afro-Caribbean men have a high risk for prostate cancer but may not be aware of their risk. Many of those studies have also demonstrated that there is a general lack of knowledge of prostate cancer among Afro-Caribbean men, and most Afro-Caribbean study participants have misconceptions of the causes of the disease, did not participate in early detection programs, and when they experienced symptoms, they either did not understand the significance of those symptoms or were reluctant to seek medical evaluation (Kleier, 2003).

It was also evident that very few researchers have looked at prostate cancer in Afro-Caribbean men overall, and little is known about the perception, beliefs, and experiences of this group. The existing data led to the conclusion that little is known about why those differences in incidence rates occur, why there is such a disparity in

incidence rates among men of the same race and ethnicity who live in different geographic areas, or how much is known about the disease in this population.

Although this study was not intended to address those questions, participants' perceptions, beliefs, and experience relative to prostate cancer may be important determinants in whether Afro-Caribbean men seek education, early detection, and treatment. It is anticipated and hoped that findings from this study will lead to an increase in early diagnosis and potentially lead to a reduction in morbidity and death from this disease.

In Chapter 3, I describe the research design, rationale, and the role of the researcher. I elaborate on the research methodology, which will include the instruments, procedures for recruitment, participation, and data collection. I also describe a data analysis plan, and finally, I describe in detail any ethical issues and procedures that are pertinent to this study.

Appropriateness of Research Method

Qualitative inquiry uses a variety of different philosophical assumptions, strategies of enquiry, and methods of data collection, analysis, and interpretation (Creswell, 2009). Among the strategies that can be used are ethnography, grounded theory, case studies, narrative research, and phenomenological research. In ethnography, a researcher studies a cultural group over an extended period of time in their natural setting by collecting observational and interview data (Creswell, 2008). Grounded theory is a strategy where the researcher builds a theory based on evidence derived from interaction with participants (Creswell, 2009). Case studies are used where the researcher

explores and focuses on one unit, program, event, activity, or process, but can involve one or more individuals (Creswell, 2009). Narrative research is applicable where one or more individuals provide stories of their lives to a researcher (Creswell, 2009).

Phenomenological research is a strategy where a researcher explores the essence of a phenomenon based on the description provided by the participants (Creswell, 2009).

I chose a qualitative approach for this study because it is a means of exploring and understanding the meaning that a group ascribes to a human problem (Creswell, 2009). In addition, because not much research has been done on Afro-Caribbean men and prostate cancer, little is known or understood about the phenomenon. In the determination of the research method, I could have chosen a quantitative survey approach, but it would not have yielded the rich and expansive data that a qualitative study could provide.

Appropriateness of Design

I employed a qualitative methodology using a hermeneutic phenomenological approach for this research. Phenomenological research involves the investigation of how an individual experiences and understands the world in which they are a part (Moustakas, 1994). Given that the goal of descriptive phenomenology is to describe a phenomenon and the general characteristics rather than individual's experiences, the hermeneutics approach allows both descriptive and interpretative aspects and therefore was more appropriate for this study.

Hermeneutic phenomenological research employs three factors in its process and analysis. Those factors are the epoché, the noema, and noesis (Moustakas, 1994). Epoché is described by Moustakas (1994) as refraining from judgment and avoiding perceiving

things in an ordinary fashion in order to keep an open mind about the phenomenon that is in front of us. Moustakas (1994) described the term noema as something that one knows and understands and the meaning a person ascribes to those things he or she sees, touches, thinks, or feels. Moustakas further noted that noema is necessary in discovering meanings that are not obvious by revisiting the information again and again. Furthermore, “noesis refers to the act of perceiving, feeling, thinking, remembering, or judging – all of which are embedded meanings that are concealed and hidden from consciousness” (Moustakas, 1994, p. 69).

Using the hermeneutic phenomenological design enabled me to explore and understand how study participants interpret information, perceive it, describe it, feel about it, judge it, remember it, make sense of it, talk to others about it, and relay their experience and the experience of others they know relative to prostate cancer (Patton, 2002). Moustakas (1994) argued that in a phenomenological investigation, researchers have a personal interest in whatever they seek to discover and therefore are intimately connected with the phenomenon. Moustakas also noted “in phenomenology, perception is regarded as the primary source of knowledge and is a source that cannot be doubted” (p. 52).

I utilized the HBM and TRA as a synthesized conceptual framework for this phenomenological study. In operationalizing the variables for the HBM and the TRA, researchers have combined the HBM concepts of perceived severity, perceived barriers, and perceived benefits with the TRA concept of beliefs and evaluation of behavioral outcomes (Poss, 2001). The commonality between the HBM and TRA is primarily based

on the notion that behavior depends on the value individuals place on an outcome as well as their assessment of the probability that a given action will result in that outcome (Poss, 2001).

Population and Sampling Procedures and Rationale

Researchers have shown that men of African descent are at a comparatively higher risk of having prostate cancer than other races. Although the results of this study cannot be generalized to the larger population of men of African descent in the United States, it looks at one segment of that population deemed to be at high risk.

Study Population

The population for this study consisted of Caribbean men of African descent who have lived in the United States for more than 10 years. This population resides in the Minneapolis/St. Paul metropolitan and suburban areas of Minnesota. Potential participants were required to be between 40 and 75 years of age. I was able to interview 13 Afro-Caribbean men who were originally from seven English-speaking Caribbean territories.

Sampling Strategy

A purposive sampling strategy was used where participants were selected because they could purposefully provide their understanding of the research problem and central phenomenon of the study (Creswell, 2012). According to Patton (2002), the logic and power of purposive sampling comes from the emphasis on in-depth understanding rather than empirical generalizations by using relatively small samples purposefully selected.

In choosing the purposive sampling strategy for this study, only homogenous sampling was seriously considered because the small homogenous group of Afro-Caribbean participants could describe in-depth the experiences, perceptions, and beliefs of their ethnic subgroup as it related to the research questions (Patton, 2002). Patton (2002) emphasized that although the findings of a study such as this should not be generalized to all Afro-Caribbean men, it would be possible to make logical extrapolations if certain criteria were met in the opinion of the reader. For example, if specific criteria were met from the readers' perspective, the reader could decide for which situations the findings might provide valid information and what degree of transferability would be appropriate (Malterud, 2001). Those criteria included, but were not limited to, adequate background material, appropriate context, study design, assumptions of the research questions, and a sound sampling strategy (Malterud, 2001).

Criteria for inclusion. The participants for this study needed to meet the following criteria:

1. They needed to be men of African descent who were originally from the English-speaking Caribbean (including Guyana) and have resided in the United States for a minimum of 10 years.
2. They needed to be between the ages of 40 and 75 years.
3. Men who met the selection criteria and were diagnosed with a prostatic condition also qualified for the study. Having a prior or current prostatic condition was not a prerequisite for this study.

Prospective participants were required to complete a demographic questionnaire (Appendix B) and a consent form (Appendix A) prior to being included in the study.

Sample size. According to Patton, (2002), “a qualitative enquiry sample only seems small in comparison with the sample size needed for representativeness when the purpose is generalizing from the sample to the population of which it is a part” (p. 244). Therefore the most important issue relating to sample size is that the researcher fully explains and justifies sampling decisions and procedures so that users would have the appropriate context for judging the sample (Francis et al., 2010; Patton, 2002).

Sample size for this study was influenced by the desire to include the perspectives of Afro-Caribbean men from as many islands as possible in an effort to capture as wide a range of views as possible. Thirteen participants were included in this study and data from all 13 were included in the analysis. I had recruited a minimum of two participants from each of seven Caribbean territories, but data saturation was reached after analyzing the data from 13 interviews.

Relationship between Saturation and Sample Size

The concept of data saturation means that a point is reached in the data collection process when no new information or themes are observed in the data (Mason, 2010). Mason noted that qualitative samples should be large enough to capture most of the important perceptions, but too large a sample may yield data that are repetitive or redundant. However, the point of saturation is difficult to identify and determine. In a study by Guest et al. (2006), the authors observed that data saturation had essentially occurred by the time they had analyzed 12 interviews. After 12 interviews, they found

that they had created 92% of the total number of codes developed for all transcripts in their study. It is important to note that in some phenomenological studies, as many as 20 or more participants were needed to reach data saturation.

Procedures for Recruitment and Participation

As the primary and only researcher for this study, I collected data from Afro-Caribbean men who met the designated criteria and agreed to participate using the one-on-one interview format. Participants were interviewed once using the one-on-one session and no follow-up interview were needed. All interaction during the interview sessions was audio recorded, but I chose not to take notes because it was found to be distracting to interviewees.

How contact information was obtained. In the review of the literature on African-American men and prostate cancer as well as other health-related studies of African-American men, churches and barber shops have been two of the primary and most convenient and effective locations for recruiting participants because of the cultural association within their communities. That cultural association was not the same for Afro-Caribbean men residing in America. For example, in Minnesota, the Afro-Caribbean community is more geographically dispersed and cricket, dominoes, carnival, and different seasonal cultural events familiar to men from the Caribbean are the main social gatherings from which to target a study group.

Participant selection. Moustakas (1994) maintained that there are no in-advance criteria for selecting participants. However, it is critical that participants must have experienced the phenomenon, are very interested in understanding its nature and

meanings, are willing to participate in lengthy interviews, are willing to permit the interviewer to tape-record or video-record the interviews, and provide permission to publish the data (Moustakas, 1994).

The selection of participants was driven by the availability of those who met the selection criteria and were conveniently located in order to be a part of this study. I also chose to interview participants from as many Caribbean territories as possible before I estimated that data saturation would be reached. The pool of Afro-Caribbean men who participated in this study were originally from the Islands of Antigua, Jamaica, Trinidad, Grenada, Barbados, St. Lucia, and St. Vincent. There was also one man from Guyana, which is considered part of the Caribbean. This group presented a set of perspectives that could be deemed as more representative of the broader Caribbean region than those in previous qualitative studies which used participants from only two or three Caribbean islands.

Format and context of the initial contact with potential participants. During the weekends every year from early May through early October, men from the former British colonies within the Caribbean as well as immigrants from India, Pakistan, Bangladesh, Sri Lanka, England, and Australia participate in a cricket tournament under the auspices of the Minnesota Cricket Association (MCA). During those weekends when cricket is played and during various weekdays designated for practice, one can find and interact with Afro-Caribbean men from at least eight Caribbean Islands who enjoy cricket as a sport.

I initially contacted prospective participants in person, followed by written communication after IRB approval as shown in Appendix C. The names, telephone numbers, and addresses of all participants were secured from each individual or provided by someone who introduced me to them. Their participation was voluntary and scheduling of interview times and locations depended on our mutual availability.

Data Collection Procedures

Following IRB approval, I contacted each prospective participant to inform them of the purpose of this study and schedule times and locations that were convenient to all parties involved. Each participant was asked to complete the following before beginning each interview: The IRB approval number is 09-05-14-0293212 (Appendix F).

1. A demographic information form which included information on age, height, weight, education in years, highest level of education attained, length of time in the United States, country of origin, employment, and known family history of prostate cancer (Appendix B).
2. An informed consent document (Appendix A). That document was given and read to them, and required their signature before they could participate in the study.

Participants were first briefed on the purpose, duration, and structure of the interviews, including the fact that each session would be audio-recorded and transcribed as close to verbatim as possible after the conclusion of each interview. Interviews were conducted for a period of 12-16 minutes and I transcribed the data with the assistance of a colleague. I also used probing and follow-up questions if it was necessary to gain a

deeper understanding into some of the responses. The information received from participants was alphanumerically coded for confidentiality.

Data collection difficulties. As the sole researcher, I envisioned that determining and securing a suitable location for the one-on-one interviews might present an issue. However, participants were willing to allow me to either come to their homes, or have the interview at my home.

Data Storage, Access, and Dissemination

As the sole researcher, I am the steward and owner of the research data, but I also consider study participants' beneficence and dignity relative to the progress and goals of this study (U.S. Department of Health and Human Services, 2006). All collected raw data, statistics, analysis, notes, and observations is saved and protected from physical damage. Notebooks and questionnaires are kept in a file cabinet in my study which is locked and to which no one else has access. All electronic data is protected by anti-virus software, password, automatic back-up software, and is saved on an external hard drive and two separate zip-drives. All research data will be kept for a period of five years to comply with Walden University's data retention policy. If I choose to destroy data after the minimum of five years, I will securely shred paper documents and erase electronic computer data.

Data Analysis

According to Patton (2002), the first step of content analysis involves identifying, coding, classifying, and labeling the primary patterns in the data. Coding involves both creating categories of the data, and describing the implications and details of those

categories (Trochim, 2006). There were several software programs available that could help with the organizing, management, and analysis of the data. I used NVivo version 10 as a qualitative data analysis (QDA) tool to help manage the transcribed interview data.

Applying Principles of Coding Using NVivo

In using the qualitative hermeneutic phenomenological process, I extracted significant statements from the interview data and created, identified meanings or meaning units, and turned them into theme clusters. My ultimate goal in using the hermeneutic phenomenological process was to establish comprehensive descriptions of empirical meaning despite the variety of terms, definitions, verb forms, and other complexities that can be a part of the interview and transcription process (Shin, Kim, & Chung, 2009). Reflective interpretation of interview data was necessary to gain a fuller, more meaningful understanding of what participants said or meant (Moustakas, 1994). The reflective-interpretative process not only included the description of participants' conscious experiences, but an analysis and interpretation of the historical and aesthetic conditions that influenced those experiences and perceptions (Moustakas, 1994).

The use of NVivo assisted in the complicated process of data comparison, verification, analysis, and synthesis. The data collected from the interviews were transcribed and sorted under each question asked in a word document format. I imported the transcripts of those interviews as "Sources" under the documents tab that is part of the external data section. I then used the auto coding option to gather answers to each question in the same place. I also created nodes to keep track of demographic information such as gender and age and kept that data associated with the responses.

Auto-coding allowed the use of the “word frequency query” to find the most commonly used words in response to each question. In order to use the auto-coding option, I employed the following a series of steps. First, I opened each interview document in edit mode. The first question and answer was then selected and saved under heading #1 within a node created called “Interview Questions.” I followed the same procedure for each other question and the corresponding answers, and saved them as “question #2” under “heading #2” etc. until all responses were saved within the interview questions node. After those steps were completed, I was able to see all the answers from each interviewee for each question by selecting the Nodes option and then choosing any question within the heading of “Interview Questions.” Those series of steps made it easier to compare the answers as well as identify the most frequently used words (NVivo 9 tutorial, 2012).

Instrumentation

Creswell (2008) noted that in-depth interviews are the primary data-collection method used in phenomenological studies. In addition, open ended interviews not only provide a description of experiences and perceptions which I was seeking to elicit, it also allowed interaction between participants and myself where I could interpret the meaning of the lived experiences (Creswell, 2008).

The primary data collection instrument that was used to address the research questions in this study was the open-ended interview using a one-on-one format. No formal instrument was used in this study as phenomenological inquiry sought to elicit the open opinions, and understand and interpret participants' experiences in order to

determine the meaning of the experiences (Touhy, 2013). For each interview, I used eight open-ended questions (Appendix D) with the option and intent to probe deeper for better understanding of responses if necessary. Each interview was recorded but I chose not to make notes during the process.

The research questions outlined in this study (Appendix D) were designed to elicit what I wanted to understand. My interview questions were intended to help me gain that understanding from the participants' perspectives. Therefore, in order to have a relatively good idea of how each interview question would work in practice, I pre-tested my interview questions with 3 Afro-Caribbean men who were not interested in being recorded as part of the study, but were willing to provide answers over the phone.

Role of the Researcher

According to Maxwell (2005), the qualitative researcher is the instrument of the research and can affect the findings because researcher perspectives and experiences can bring bias to the study and its findings. However, Moustakas (1994) emphasized that personal history can also bring the core of the problem into focus. As the sole researcher, I am responsible for gathering the data, making sense of it, and organizing it into categories or themes. In spite of the goal of being objective, my interpretation of what I hear or understand can be subject to researcher bias, and may not be what participants meant during the interview process.

One of my roles as a researcher is to use member-checking to ensure that what I hear, record, and write are what interviewees actually said or meant. In two situations, I was uncertain about the meaning of statements in two participants' responses and I

followed up with those participants to explain further. I also told participants at the beginning of each interview to feel comfortable asking for further explanation if they did not fully understand the questions asked.

Member-checking gives participants the opportunity to correct errors and dispute what they may perceive as misinterpretations. In addition, it affords the opportunity for participants to volunteer additional information which may be stimulated by reading the transcribed data (Cohen & Crabtree, 2006). As part of the member-checking process, each participant was offered the opportunity to review the transcribed information specific to his interview responses for accuracy. A total of eight participants reviewed the transcripts but only one made changes because he was not happy with the verbatim grammar used. None of the participants made content changes to the transcripts.

Researcher's Relationship with Study Participants

For this phenomenological study, I employed a purposive sampling of Afro-Caribbean men between the ages of 40-75 years who have resided in the United States for more than 10 years. These men all reside in the Minneapolis/St. Paul metropolitan area and surrounding areas of Minnesota. As the only researcher for this study, I identify ethnically and culturally with prospective participants, as I am a part of the Minneapolis/St. Paul Afro-Caribbean community and social network.

Glesne & Peshkin (1992) referred to research where friends and colleagues are the primary participants as “backyard” research, which can compromise the researcher’s ability to disclose information, as well as raise power issues. It is therefore possible that

participants were more or less apt to disclose personal information because of the pre-existing relationship between the participants and myself as researcher.

Glesne & Peshkin (1992) emphasized that although the incorporation of researcher experience and perspective is not a license to impose his or her assumptions and values into the research, experience makes researchers who they are as people, and equips them with perspectives and insights that shape everything they do as researchers.

In order to establish researcher credibility, I have reported all personal and professional information that may affect participant selection, participant responses, data collection, analysis, interpretation, and conclusions (Patton, 2002). In addition, I take my responsibility as the researcher seriously and strived to neither overestimate nor underestimate any effect I may have had on participants' responses.

Ethical Issues

Qualitative researchers face several ethical issues that can arise as part of the data collection, data analysis, and dissemination process (Creswell, 2012). As it relates to this study, the primary ethical issues were those of informed consent, confidentiality, data protection, storage, dissemination, and my sharing personal experiences during the interview that may have influenced the data collected. Issues of privacy, data storage, and the voluntary nature of the study is addressed through the informed consent agreement (Appendix A).

Demographic Questionnaire

The demographic questionnaire (Appendix B) is comprised of questions that relate to participants' age, marital status, education, income, country of birth, and

perception of general health with greater specifics related to prostate health. Those variables are modifying factors that help determine participants' perceptions of benefits and risks associated with screening and taking preventative actions.

Demographic information is important because there are several demographic criteria essential for participation in this study. There is a minimum and maximum age requirement, participants must be of African descent and be originally from the Caribbean, and participants must be residing in the United States for a minimum of 10 years. Although this study was not designed to analyze nor suggest an association between variables such as educational attainment, general perception of health, marital status, and beliefs and perceptions of prostate cancer, that information was helpful in providing deeper insight into who study participants are.

Issues of Trustworthiness

Credibility (Internal Validity)

Patton (2002) noted that there are several ways to establish credibility. For this study, I consciously searched for alternative themes, divergent patterns, and rival explanations that support alternative explanations. One way I chose to accomplish this was by using the search facility in the NVivo software. When the data were searched in terms of attributes, such a search electronically yielded more reliable results than doing it manually primarily because human error is ruled out. However, in order to achieve the best results, I used both electronic and manual methods and combined the best features of each.

As the sole researcher, I made my biases and predispositions explicit and provided candid details about my connections with participants. I also discussed experiences related to the research that might affect reflexivity, data collection, analysis, and interpretation (Patton, 2002). According to Guba (as cited by Creswell, 2008), member-checking is viewed as the most critical technique for establishing credibility. As a form of triangulation, I used member-checking and sought respondent validation by providing participants with the opportunity for final input and to make necessary corrections to ensure that their intent and meanings were accurately captured (Maxwell, 2005).

Transferability (External Validity).

The purposive sampling strategy used in this study was intended to include participants from as many English-speaking Caribbean islands as possible with the possibility for extrapolation in mind (Patton, 2002). Although the views of such a small purposively selected group cannot be generalized to Afro-Caribbean men in general, the findings can be transferable if the reader was satisfied that background material such as demographics and study setting provides a context that allows them to decide for which situations the findings might provide valid information (Malterud, 2001).

Goetz and LeCompte (as cited by Huberman and Miles, 2002) also argued that qualitative studies can gain the potential for applicability to other situations if the reader is satisfied that components in the study are well detailed, and the theoretical position and research techniques are clearly described.

Dependability (Reliability).

In order to enhance dependability, a good quality audio-recording device was used, and I made sure that a detailed and exact transcription of the recordings was saved. Transcription was done directly from each tape recording and checked and re-checked for accuracy. One of the main issues with dependability is the need for agreement of multiple coders of data sets. That was not an issue in this study as I was solely responsible for conducting the research and associated coding.

Confirmability (Objectivity)

As Maxwell (2005) contended, “the fact that the researcher is part of the world he or she studies...is a powerful and inescapable influence” (p. 109). That was an important threat to validity in this study because of my prior relationship with some of the study participants. To minimize that influence, I avoided asking leading questions. For example, I avoided asking questions such as, “Don’t you think it would be a good idea for your physician to recommend PSA testing for every Black man over 40 years?” I also consciously tried to understand how I might be influencing what participants say, and how my influence affects the validity of the inferences I draw from the interviews (Maxwell, 2005). In addition, my documentation of experiences and possible researcher bias and predispositions will help readers determine the objectivity of the results.

Treatment of Discrepancies

Identifying and analyzing discrepant data is an essential part of validity testing (Wolcott, 1990). As the researcher for this study, I rigorously examined both supporting

and discrepant data to see if it was more plausible to retain the conclusions or report the discrepant information and allow readers to make their own conclusions (Wolcott, 1990).

Sharing Results with Stakeholders

After each interview was concluded, I debriefed participants by informing them of how the results will be used. I also provided contact information and obtained their permission to contact them in case I needed clarification on their responses, required a follow-up interview, or had additional questions. I used member-checking as an important strategy for checking accuracy and credibility (Creswell, 2008).

Conclusion

I chose a qualitative methodology using interviews as the data collection tool because that methodology allowed collection of extensive detail about participants' views, flexibility in sample size, how participants interpret and process information about prostate cancer, and how they relay their experience relative to the disease. It was important to describe my role as the researcher in detail as my relationship with potential study participants could possibly affect the dynamics of the interview process and influence how the data is interpreted.

The purpose of this qualitative, phenomenological study was to explore and analyze the perceptions, attitudes, experiences, and perspectives of a sample of Afro-Caribbean men who are at risk for prostate cancer and reside in the United States. This study was aimed at capturing how a cross-section of Afro-Caribbean men perceive prostate cancer-related issues such as their susceptibility and risk, early detection testing, benefits and risks from such testing, and how they get their prostate information. This

study is the first qualitative of its kind in the United States that targets men from as many as seven different English-speaking Caribbean islands, and is therefore more representative of a broader Caribbean view on the disease.

Summary

In Chapter 3, I described the research design, rationale, and my role as the researcher. I discussed in detail the research methodology, which included the instruments, procedures for recruitment, participation, and data collection. In discussing the appropriateness of the research method and design, I briefly outlined the various strategies and approaches that could be used in qualitative inquiry and determined that a hermeneutic phenomenological approach would be the most applicable for this study. I discussed the population sampling procedures and rationale for sampling strategy, sample size, and procedures for recruitment and participation in this study.

I outlined the steps that need to be taken in terms of data collection and specifics on how data will be stored, disseminated, and destroyed based on Walden's data retention policy. I also described a data analysis plan using NVivo as the qualitative data analysis tool. Finally, I provided details on the role of the researcher with particular emphasis on my relationship with study participants, ethical issues, and issues of trustworthiness which may affect the legitimacy of this qualitative study.

Transition to Chapter 4

Chapter 3 described the research methodology. In Chapter 4, I describe the results and findings of the study and collection and analysis of the data.

Chapter 4: Results

Introduction

The purpose of this qualitative, phenomenological study was to explore and analyze experiences and beliefs about prostate cancer in a sample of Afro-Caribbean men between the ages of 40 and 75 years old who reside in the United States. Three specific research questions were outlined in an attempt to determine the lived experiences of Afro-Caribbean men and their perceptions of risk, risk factors, prevention, detection, and treatment of prostate cancer. One of the research questions was intended to determine if, and to what the extent, culture affected those lived experiences and how it influenced their motivation to undertake screening or seek treatment. In Chapter 3, I discussed the research methodology, the appropriateness of the research method and design, and the various strategies and approaches that could be used in qualitative inquiry. I also described the population sampling procedures, the rationale for the sampling strategy, sample size, and procedures for recruitment and participation in this study. In addition, I detailed a data analysis plan that included using the NVivo 10 software as the qualitative data analysis tool. In Chapter 4, I restate the research questions and research methodology and describe the results and findings of the study.

Sampling Logic

A total of 19 men aged 40 to 75 who were originally from eight English-speaking Caribbean territories and currently reside in the United States were purposively selected for this study. Of those, 13 participants from seven Caribbean territories were interviewed and the data used for analysis. A purposive sampling strategy was used

because participants could purposefully provide their understanding of the research problem and central phenomenon of the study (Creswell, 2012). Patton (2002) noted that the logic and power of purposive sampling comes from an emphasis on in-depth understanding rather than empirical generalizations. Patton also pointed out that such in-depth understanding can be facilitated by using relatively small sample sizes. As outlined in Chapter 3 of this research, each participant needed to meet specific criteria in order to qualify for this study. Although the findings of this research cannot be generalized to all Afro-Caribbean men, it is possible to make logical extrapolations if readers of this study can decide for which situations these findings might provide valid information, and the degree to which transferability is appropriate (Malterud, 2001).

Data Collection

Twenty seven men were identified and approached in the spring of 2014 as possible participants for the study; however, only 19 agreed to participate, and data were collected from 13 participants. Four of the participants play cricket in a summer league in a Minneapolis suburb, and so it was not difficult to get their initial agreement and schedule the interviews. Those four participants assisted me in recruiting other participants from several other Caribbean territories. Interviews were scheduled based on participants' willingness and availability and conducted at their homes, their workplace, or my home.

Data were collected through individual face-to-face interviews using a series of open-ended questions that I created and pretested as the researcher. According to Patton (2002), the general purpose of interviews is to gather other peoples' perspectives, but the

quality of the information obtained depends largely on the preparation, listening, communication, and other skills of the interviewer. A sample list of those questions was approved through the IRB approval process as part of the Consent Form (Appendix A), and the full list of questions is shown in Appendix D. Each participant interview lasted approximately 12 to 16 minutes and data were recorded using a hand-held tape recorder.

In order to facilitate a smooth and easy-to-follow set of questions, I prepared an interview guide that contained topics and subtopics designed to help me freely explore, probe, and ask follow-up questions that would solicit the kind of information needed to address the research questions. In an attempt to determine if the questions addressed the research questions, interview questions were first asked to three volunteers who met most of the criteria for the study but did not want to participate in the research. During the actual interviews for this research, additional questions were asked either to clarify the previous question asked, to follow-up on answers that were provided, or to encourage an expanded or unique perspective.

Prospective participants were emailed or mailed an Invitation to Participate letter (Appendix C), and that letter was followed up with a phone call 1 to 2 weeks later. In an attempt to gather data from as many Caribbean islands as possible, a minimum of two participants were contacted from each of seven different islands and the country of Guyana, which is considered a Caribbean territory. However, only one participant was interviewed from four of the territories because no new themes emerged after 13 interviews were conducted.

Interviews were conducted over a 2-month period either at the participants' homes or at my home beginning in mid-September 2014. Before starting each interview, I explained the purpose of the study, ensured that they understood that the interviews would be recorded, and summarized the potential benefits of the findings. I also had each participant complete a demographic data form (Appendix B) and sign a consent agreement (Appendix A) prior to commencing the interviews. Finally, I verbally informed them that they had the option of member-checking the transcribed data if they were willing to do so.

Each interview was recorded following the set of questions that I prepared (Appendix D). However, questions were not necessarily asked in the same order to each participant because in some cases, an answer to one question required a follow-up question that helped expand on or clarify the previous answer. In several cases, some participants were asked as many as 12 questions because it was necessary to ask sub questions and follow-up questions. I chose not to take notes during the recorded interview sessions because I found that it was distracting to the flow of the conversation and I wanted to give my full attention to all participants.

All information recorded and transcribed was that of the participants, and each recorded session is stored on an external hard-drive, a zip-drive, and my lap-top computer where the files are password-protected. Each participant was given a name such as Participant A in order to identify his specific information, while allowing his identity to be private. I solicited the help of a colleague to transcribe the data, but transcription was particularly difficult because of the unique and sometimes difficult-to-understand dialects

and accents of some of the participants. It was therefore necessary to repeat many sentences multiple times as we listened to the recordings, and the transcriber typed in order to ensure accuracy. Hard copies of the transcribed data, consent forms, demographic information, and any notes pertaining to the data collection process are kept in a folder and stored in a locked file cabinet in my study at home. The NVivo software program also facilitated storage of the recorded and transcribed data, and these data are stored within the software program on my lap-top, zip-drive, and external hard drive.

Demographic Profile of Participants

The participants in this study included 13 Afro-Caribbean men from seven Caribbean territories aged 40 to 75 years who have resided in the United States for a minimum of 10 years. Participants were from the territories of St. Kitts/Nevis, Barbados, St. Lucia, Trinidad, Antigua, Jamaica, and Guyana and their demographic information is represented in Table 1. Of the 13 participants, two were between the ages of 40 and 49 (15.4%); five were within the age range of 50 to 59 (38.5%); and six were within the age range of 60 to 69 (46.2%). Seven (53.8%) reported that they were in good health, four (30.8%) stated that they were in excellent health, one (7.7%) said that he was in average health, and one (7.7%) described his health status as poor.

Educational attainment ranged from completing high (secondary) school to completing graduate school. Three (23%) attended school for 12 to 15 years, which is equivalent to completing high school; six (46%) attended school for 16 to 19 years, which is equivalent to attending or completing college; and three (23%) attended school

for 20+ years, which is equivalent to participating in or completing a graduate degree program.

Table 1

Demographic Characteristics of the Sample

Participant	Years of school	Age Group	Marital Status	Country of Birth	State of Health
B	16	40-49	Single	St. Kitts/Nevis	Good
G	17	60-69	Married	Antigua	Excellent
C	12	50-59	Single	Antigua	Excellent
M	18	50-59	Married	Barbados	Good
D	10	60-69	Divorced	Antigua	Poor
H	20+	50-59	Married	Jamaica	Average
K	15	50-59	Married	Trinidad	Good
L	14	40-49	Married	Jamaica	Good
J	20+	60-69	Married	Guyana	Excellent
E	19	50-59	Married	St Lucia	Good
I	20+	60-69	Married	Jamaica	Good
A	17	60-69	Married	Jamaica	Good
F	19	60-69	Divorced	St Lucia	Excellent

As shown in Table 2, participants conveyed information relating to their physical exams and screening for prostate cancer. Twelve men (92.3%) had a prostate exam of some kind. Eight (67.5%) had a Digital Rectal Exam (DRE), seven (53.8%) had a PSA test, and four (30.8%) had both a DRE and PSA test. Only one participant (7.7%) reported that he did not have any kind of prostate cancer test and one participant (7.7%) was unsure of what kind of prostate cancer test he was given.

All participants had a physical exam within the last 5 years of which three (23%) had a physical examination 1 to 2 years ago, eight (61.5%) had a physical less than 1 year ago, and two (15.4%) had a physical more than 2 years ago. Twelve participants (92.3%) stated that they planned to get a prostate cancer test in the near future, with 4 (33%)

indicating that they will do so within the next 6 months, and seven (58.3%) within the next year. Only one participant (7.7%) stated that he did not plan to get any kind of prostate exam in the future, and two (15.4%) were unsure of when they would get tested.

Table 2

Demographic Variables Relating to Prostate Cancer Testing

Participant	Last physical exam	Prostate Test	Type of Test	Plans for Test	How Soon Plan for Exam
B	1-2 years ago	Yes	DRE	Yes	Within 6 mths
G	1-2 years ago	Yes	DRE	Yes	Within 6 mths
C	less the 1 year ago	Yes	DRE	Yes	Within 1 year
M	less the 1 year ago	Yes	PSA and DRE	Yes	Not Applicable
D	less the 1 year ago	Yes	PSA and DRE	Yes	Within 6 mths
H	More than 2 years ago	Yes	PSA	No	Not Applicable
K	less the 1 year ago	Yes	Unsure	Yes	Within 1 year
L	less the 1 year ago	No	Not Applicable	Yes	Within 6 mths
J	less the 1 year ago	Yes	PSA and DRE	Yes	Within 1 year
E	1-2 years ago	Yes	PSA	Yes	Within 1 year
I	More than 2 years ago	Yes	PSA and DRE	Yes	Within 1 year
A	less the 1 year ago	Yes	DRE	Yes	Within 1 year
F	less the 1 year ago	Yes	PSA	Yes	Within 1 year

Note. < Less than; > More than.

In terms of participants knowing anyone with prostate cancer, Table 3 shows that 11 (84.6%) participants knew someone who had or currently have prostate cancer. Of those, four (30.8%) were relatives, six (46.2%) were friends, and one participant (7.7%) knew patients who had or were currently battling prostate cancer. Table 3 also shows how participants got their information on prostate cancer. Eleven (84.6%) stated that they obtained it from their physician, four (30.8%) got it online, one (7.7%) got it from a friend, two (15.4%) from reading, and one (7.7%) got it from his workplace.

Table 3

Relationship to Person with PC and How Information on PC Was Obtained

Participant	Know of Someone withPC	Relationship	Info on Prostate Cancer
B	No	Unassigned	Doctor
G	Yes	Friend	Doctor and online,
C	Yes	Friend	Doctor
M	Yes	Brother	Doctor and online,
D	Yes	Friend	Nurses, Seminar, doctor,
H	Yes	Patient	Work, online, doctor, readings
K	Yes	Friend	Doctor
L	No	Not Applicable	News
J	Yes	Friend	Doctor
E	Yes	Uncle	Doctor and online,
I	Yes	Uncle	Doctor and readings
A	Yes	Friend	Friend
F	Yes	Brother	Doctor

Research Questions

The purpose of this qualitative, phenomenological study was to explore and analyze beliefs about prostate cancer in a sample of Afro-Caribbean men between the ages of 40 and 75 years old who reside in the United States. The aim of the phenomenological approach was to determine what an experience meant for the persons involved and their ability to provide a comprehensive description of that experience or perception (Moustakas, 1994).

The findings presented in this chapter are focused mainly on addressing three research questions that were intended to better understand Afro-Caribbean men's experiences, perceptions, and beliefs relative to prostate cancer.

Research Question 1

What are the lived experiences of Afro-Caribbean men relative to prostate cancer?

Research Question 2

What are the perceptions of risk, risk factors, prevention, detection, and treatment of prostate cancer?

Research Question 3

To what extent, if any, does culture affect the lived experiences, beliefs, and motivation to act relative to prostate cancer for Afro-Caribbean men?

Data Analysis**Applying Principles of Coding Using NVivo**

NVivo 10 is an important data analysis tool that was used to assist in the organization and management of the transcribed. After each interview was concluded, I listened to the responses at least three times before having the interview transcribed. After the data were transcribed, I reread the information while listening to the recording to ensure accuracy. To enhance credibility, I emailed the transcribed data to eight participants for whom I had email addresses and encouraged them to read the transcribed information for accuracy.

Transcripts of the recorded interviews were imported into the NVivo 10 program, and I used the auto coding feature to gather answers to each question in the same place. The “word frequency query” was used to discover the most commonly used words in response to each question. In order to use the auto-coding option, I used the following

series of steps. First, each transcribed interview document was opened in edit mode; the first question and answer were selected and saved it under heading #1 within a node created called Interview Questions. The same procedure was followed for each other question and corresponding answers, and were saved as “question #2” under “heading #2” etc. until all responses were saved within the interview questions node. After this was completed, all the answers from each participant for each question were shown by selecting the Nodes option and then choosing any question within the heading of Interview Questions, making it easier to compare those answers as well as the most frequently used words.

Presentation of Themes

After importing the transcribed data into NVivo 10, I then proceeded to identify categories and themes. Data were organized based on responses to each question with the objective of identifying consistencies, differences, and discrepancies between participants’ responses. That allowed me to analyze the data and create categories that were smaller and more manageable for the purpose of analysis.

I reviewed each transcribed interview, building categories and identifying themes until no new themes were obvious. My original goal was to interview at least two participants from each territory but no new themes were evident after 13 interviews. It, therefore, seemed unproductive to proceed with conducting the six additional interviews that were scheduled since data saturation was reached. The saturation assertion seemed consistent with a study by Guest et al. (2006) where the authors observed that data saturation had essentially occurred by the time 12 interviews had been analyzed. After 12

interviews, the authors found that they had created 92% of the total number of codes developed for all transcripts in their study (Guest et al., 2006).

Themes Associated With Research Question #1.

For Research Question 1, I sought to address the following: “What are the lived experiences of Afro-Caribbean men relative to prostate cancer?” Participants were asked several different questions meant to address Research Question # 1 and the following three themes were evident: Awareness has a lot to do with it, it’s a Matter of Attitude, and if something is wrong, my doctor will tell me

Theme 1: Awareness and education have a lot to do with it. The first theme “Awareness has a lot to do with it” was expressed in several different ways, but was directly related to the admission by most participants that they know very little about prostate cancer, how it is contracted, the symptoms, and how to manage the disease if they were diagnosed with it. Although participants were not asked to distinguish between education and awareness, it was evident that several of them saw a difference between the two as expressed in several of their responses.

Most of the participants conveyed that they did not have a high level of awareness of prostate cancer, and most of what they heard was from the news or from their physician. None of the participants in this study had been diagnosed with prostate cancer and so their assessment of the lived experiences was based on hearsay, the experience of someone they know, and their perception of how the disease would affect them if they had it. For those who knew someone with prostate cancer, they expressed that their level of awareness was heightened after that discovery.

Participant L described his understanding of the importance of awareness:

Well, just as to general health. Cancer doesn't just sneak up on you so if there is an issue or a high probability out there, it would be nice to know about it so that you can get checked for it. Now that I'm aware of it now, it's something that in my consciousness to get checked for, but at the moment, it's something that doesn't sneak up on you where you can't be treated for it if it's too far. So I'm just looking forward to getting any additional information about how it would affect the community and stuff like that. For Afro-Caribbean men, once we are conscious of the disease, it's a matter of information that affects the community. Once you brought it to our attention, it's in our consciousness.

In addition to the lack of awareness, several participants stressed the importance of education relating to the disease. Based on several answers, some participants demonstrated an understanding of a difference between awareness and education. As Participant E described it,

If you can open yourself to widening your scope of education with regards to prostate cancer, I think it can help you a lot more in dealing with the problem than if you don't know as much. I think if you prepare yourself and you know you need to change your eating habits...., if you're a smoker, you need to stop smoking....things like that and change your lifestyle. Changing what you eat, what you drink, and things like that will go a long way in helping with the recovery process.

Similarly, Participant A described why awareness and education are important, but went further in terms of talking some of the ramifications of not being educated about the disease,

Awareness is important in terms of education of the ramifications of what prostate cancer is and what it will do to you in the future, because if you are an active person and this thing affects you and gets worst, you cannot do anything....you become an invalid and a problem to everybody around you.

I think that if they get the information and awareness, anybody would welcome a test that could prevent problems in the future. I think it's just that people are not being aware and sometimes the educational level is an issue.

Participant M expressed his opinion that "people in general conclude that if they are not aware of a problem, then it's not a problem." He continued that "people would prefer not to know about a problem than find out they have a problem and therefore they would have to deal with it."

Despite the fact that most participants admitted limited knowledge and awareness of prostate cancer, most of them mentioned that if you catch the disease early, the chances of survival are much better. Speaking from a general understanding of managing any type of cancer, Participant L expressed,

Generally with cancer, the sooner you catch cancer the better. Obviously if you catch it in the beginning stages, you can have a long life. If you catch it in the middle stages then you can fight the battle. But if you catch it in the end stages, then your time may be limited. So when it comes to cancer, it depends on when

and in which stage you catch it. Cancer is a thing you can live with depending on how soon you catch it.

Similarly, Participant H contended that,

I now know that no matter what kind of cancer you get, if you don't treat it, or treat it early enough, your chance of survival is not very long.... or I just think that no matter what kind of cancer you get, if you find out about it early, have it treated early, then your chance of survival is a lot greater.

Participant D was more pessimistic about survival from the disease and estimated that regardless of when the disease was caught, the chances of survival was low and limited to two or three years. He pointed out that this opinion was based on how someone he knew with prostate cancer was currently doing. However, he also conceded that the sooner the disease was caught the better, and similarly stated that,

Back home, a couple of people still die a lot from it. My buddy got diagnosed in February last year and I can tell you that as we are speaking here, I don't think he is doing too well. So I think [you can survive] maybe two or three years, but I could tell for a fact if you catch it early you live a little longer.

Theme 2: It's a matter of attitude. Several participants noted that how Afro-Caribbean men approach testing and management of the disease is influenced by their attitude. A few of the men interviewed for this study stated that their attitude toward prostate cancer testing, management of the disease, and prostate cancer in general was influenced or changed after they had a family member or friend diagnosed with any type of cancer.

Participant K described his change in attitude about going to the doctor after his wife was diagnosed with breast cancer and subsequently had a mastectomy. He described that change in the following words,

I was reluctant to do a colonoscopy but after seeing my wife come down with breast cancer and seeing what she had to go through, I decided that if I wanted to be around to take care of my wife and family, I'd better go and do this.

Most participants described their attitude towards testing in general and noted that they had no issues with getting a test for prostate cancer, but had some hesitancy about the DRE. Although the issue of the DRE was seen as an unwelcome and humiliating intrusion, all participants who knew what screening was for stated that their attitude was softened once they were told what the test was about.

Participant M explained,

The first time [I got a DRE] I was very uncomfortable. I mean, we are not accustomed to things like that, but after I understood what prostate cancer was and I knew a little about it, I understood why it was being done and I'm glad that he is doing this, especially after my brother was diagnosed. I want to know if I have it so that I can do whatever I have to do to get it taken care of.

Participant D described his attitude to the DRE as follows,

I have a friend back home who said this is about his health and even if they were going to put their foot [in his anus], he would still have it done because it's for his health. He's not alone saying that. It's a procedure to conquer the problem.

Well, they think in terms of “anti-man business,” like homosexuals. I don’t see it that way. Women go to the clinic and gynecologists for pap-smears and all that so if this is our pap smear, we should do it.

Participant I explained how he thought most Jamaican men perceived the DRE, Most of them are [hesitant] because they are concerned with the intrusion process. They don’t want the doctor to do the intrusion type testing. They have a way of thinking that, “No, no, I’m not going to go there. I am fine. I am macho.”

Similarly, Participant A stated, “I don’t think they don’t want to get tested, but some men don’t want men touching their genitals and stuff like that.”

Participant L described coming from a culture where people don’t like to take or add anything to their body. Despite confusing testicular cancer with prostate cancer, he stated that the goal would be to catch a disease such as prostate cancer at the first sign or symptom. Participant L went on to discuss his attitude to some of the issues associated with testing because of the probable longer term health benefits for himself and his family,

Well, there is probably the stigma of the whole anal intrusion in the culture. With the anal intrusion, I think the idea should come up that this is how prostate cancer may affect your life and if you do this, it may help you. Then they will be more likely to get tested and don't mind the anal intrusion if it's going to help me and my family in the long run. So if shown the benefit, then they will be more likely not to mind...

Theme 3: If something is wrong, my doctor will tell me. In response to questions related to how participants acquired knowledge of prostate cancer, several of them talked about the relationship they have with their physician and how that impacted whether they got tested, their knowledge of the disease, and their risk of being diagnosed with the disease. As shown in Table 3, the majority of participants (84.6%) noted that they got most of their information from their physician. However, several participants also contended that the topic of prostate cancer did not come up during their physical exams.

Participant M was pleased with his relationship with his physician, but despite having regular tests relating to his prostate, he noted that,

He [My doctor] did it from the rectum and he checked to make sure that my prostate was not enlarged and stuff like that. I don't know what my PSA is. I checked my medical records but I don't see it in there.

Several other participants described their relationship with their physician as positive and noted that they depend on their doctor not only for information about prostate cancer, but they are sure that if there was anything they need to know medically, their physician would convey it to them. Participant M was particularly emphatic about the trust he places in his physician and stated,

I go to the doctor fairly often and I'm sure he would have told me. I have a blood test every time and I know he has them run all the tests. I don't think about it a whole lot and as long as I get tested and my doctor tells me that there is no problem, I figure there is no problem. He [my doctor] is thorough. Every 3, 4, or

5 years, he will give you a full run down of all the tests. He gets a cardiologist involved, he gets an endocrinologist involved, and he gets everybody else involved. So within a 5 or 6 week period, they will schedule these exams with all these different people.

Participant A stated that he would let his doctor take the lead in any discussion regarding prostate cancer. He described his relationship with his physician as a positive one where his physician would ask specific questions about prostate related issues. Participant A noted that he believed those questions were initiated because of his age given that he is 63 years old.

Most participants expressed their views of men and “going to the doctor.” Several of them talked about the reluctance of men in general, particularly Afro-Caribbean men, relative to going to the doctor unless they were physically ill. Participant H stated that he did not think that people from the Caribbean, whether its men or women, actually seek to be tested for anything unless they get very sick. He continued that “we are just in general too laid back and...we don’t take our medical health as seriously as we should.”

Participant J echoed the view that men are reluctant to go to doctors, but also expressed the opinion that the length of time living in the United States increases the probability of visiting the doctor more frequently and subsequently, increases the likelihood of getting tested. Participant J asserted that,

I think men in general tend to shy away from doctors and tests and so I don’t think this will be any different than in the Afro Caribbean population. I think it

falls into the general behavior of men and being from the Caribbean they are more likely not to be tested because of the stigma associated with it. The longer an Afro Caribbean man lives in the United States, their attitudes will probably be softened and they are more likely to get tested. I know my brother-in-law, who is quite a few years younger than I am, just got detected with prostate cancer and he discussed it with me and he is very aggressive in his treatment. I was surprised because I always thought he was on the macho side of it. I was really pleased with how he addressed the concern when it arose.

Participant L was particularly explicit about his views about visiting doctors in general. This participant had never received a prostate cancer test and contended that his physician should have been more pro-active in helping him be more aware as well as recommending or conducting tests for the disease. He also talked about the limited time doctors have to give to patients. Participant L stated,

I think doctors today expect patients to come to them with the problem. They are not in the preventative state. So, being in America, I need to adopt the mentality that I have to take it upon myself and say, "Hey I want to get tested for the anal disease.... I want to get tested for this or that." I find that when I go to a male or female doctor, I believe that my services are less with a male doctor. So for me, I find that I need to be conscious medically about getting tested for this or that because when I go to the doctor's office, he only has about 10 minutes, so if you don't put your thing on the table, he's not going to be thinking about it. So your health is in your hand. He [my doctor] would say, we are going to do a PSA test.

This is what your numbers were last time. He would ask questions about how I feel, how is my urinal flow, do I need to get up at night to urinate, how many times do I get up to go to the bathroom during the day or night but those things never come from me.

Participant E described a specific situation for which he needed to see his physician. He talked about why he modified his perspective on going to the doctor and having a prostate cancer screening. He said,

I did have an issue one time where I had a swollen prostate and I did go to the doctor where I was told I had a swollen prostate and I needed to basically monitor it. However, having that experience forced me to go see a doctor which I would have never done otherwise. I mean...I have had colonoscopies but I never would have asked for a test for prostate cancer.

Themes Associated With Research Question 2

For Research Question #2, I sought to answer the following: What are the perceptions of risk, risk factors, prevention, detection, and treatment of prostate cancer? Participants were asked several different questions that were meant to address Research Question # 2 and the following eight themes were evident: I know very little about the disease, I don't worry about it, If I got the disease I would be concerned, my family is important, you can still live a long live if treated early, prostate cancer may affect my lifestyle, start treatment early and follow the doctor's advice, and finance and health insurance can be burdens.

Theme #1: I know very little about the disease. The majority of participants in this study stated that they knew very little or nothing about prostate cancer, its symptoms, and its side effects. One of the participants is a nurse and so he had a more enlightened view from a clinical perspective and the likelihood of survival given adequate treatment.

Several participants associated the diagnosis of prostate cancer with being poor, diet, age, having multiple sexual partners, working around or inhaling chemicals, and genetics. It was also evident that some participants confused prostate cancer with testicular and colon cancer and assumed that a colonoscopy and a test for prostate cancer were the same and were meant to achieve the same result. Most participants stated that prostate cancer is deadly and admitted that there are several factors that impact one's ability to survive after contracting the disease. However, the majority of participants contended that chances of survival were good if the disease was diagnosed in the early stages.

Participant A conceded that he did not know anything about risk factors and described his knowledge as,

What I know and I've heard that people who are afflicted with this situation are sometimes poor people, and they don't really get annual physical exams to detect these things early so that they can put in preventative measures. What I understand also is that diet has something to do with it, and multiple sexual partners could have something to do with it. That's what I've heard. But it seems like a lot of people get afflicted with this situation because they don't get medical check-ups on an annual basis and so sometimes when they do find out, it's too

advanced to do anything...but it looks like some of this can be also genetics and also it could be just the regular routine things you need to do to sustain a long life that could prevent some of the problems associated with this situation.

Participant F also conceded that he knew little about the disease.

Just from a layman's knowledge...I don't know much about the technicalities about prostate cancer but that it disproportionately affects people of African descent more so than white people.

Participant I is a school teacher who seemed to know more than most of the other interviewees. Based on the entire interview, he seemed very pro-active about his health and that of his family. He described what he knew about prostate cancer:

Every man has a prostate gland and based on research at the University of Minnesota, I am aware that at some point, every man's prostate will enlarge at some point. I also heard that when the prostate enlarges, there's a problem with peeing because it pushes against your urinary gland and it prevents you from peeing freely. If the prostate gets enlarged and isn't treated, it can become cancerous. The prostate needs to be tested, as early as 30 years old. I know a gentleman who had a prostate issue what was barely past 30. A doctor did a DRE on me about 5 years ago and I asked him, "What are you checking for?" He said he was checking for polyps, to see if there are any bumps in there and it hurts a little when he goes against the gland. There's also the blood test which is a PSA, prostate specific antigen. If your number is four or above, you are in danger of getting prostate cancer. Your number should read below four. Last time I checked

my number, about a year ago, it was about 1.3, something around there. I do what I can to take care of my prostate. I also know that your prostate can show your libido, your sexual situation. If your prostate is bad, it may also affect your sexual life. One has to take care of one's prostate. If you are in your twenties, do the right thing, take the right pills and get your test, rather the intrusion test, get the blood test.

Participant J noted that because of his age, he had discussed it during typical checkups and his doctor told him of the need to do a PSA. He said that his doctor also discussed what the PSA results mean and what the receptors were. Participant J conveyed his thoughts on prostate cancer causes and symptoms,

I'm not sure what the causes are. I know that from going to checkups with doctors that typically Afro American men are more susceptible to get prostate cancer. I had a history of cancer in my family so it's something I should be aware of. Also we talked about the value of doing a PSA, as an early indication of prostate cancer, etc. So just typical checkups, information from the doctor about the need to do a PSA was discussed with me along with what the PSA results mean and what the receptors are. Other than that I really haven't done any research on it. So to reiterate I just know that the information from the doctor, typically African American males, especially in my age group, have tendencies to show a higher risk than normal population.

Participant H is a nurse and presented his understanding of the disease from the perspective of having observed several patients after prostate cancer surgery. He

described the debilitating side effects and the sometimes rapid demise of such patients after such surgery:

I've seen a lot of problems prostate cancer patients have after having surgical intervention . . . a lot of dribbling, a lot of incontinence. I've seen people's overall well-being decline to the point where they actually die eventually. It seems to happen faster than for a normal individual going thru surgical recovery; it seems as if the downward process is speeded up so I can tell you that it is something I hope I definitely don't have to deal with because it's just one of those medical problems that's difficult to deal with.

Similarly, although Participant D expressed the preventative measure he takes based on his knowledge and the experiences of two friends with the disease:

Well, I know that prostate cancer is deadly. Prostate cancer can be caused by a lot of different things. You can be born with it, so most likely it can develop when you get on in age, like 50 and up. I know two of my friends right now suffer from that so it's got to be true with the study that they have. I don't know, so I just go and check myself every year. Sometimes twice a year, both ways, with the blood and a finger exam. I try to keep myself in line like that.

Participant G described his increased awareness and knowledge of the disease because a close friend was diagnosed with prostate cancer. He stated,

It was a close friend so the first thing is that it was surprising. I mean, it's not something that you think about. You think about prostate problems but not prostate cancer. I know many people who have had prostate problems with

urination and all those kinds of stuff but not the cancer part. I don't know how they are related. It was impactful because it was a young person. You always think that prostate cancer was kind of something old men get. That's the kind of attitude or something like that but then you figure out its possible anytime and anyone can get it. It was kind of a realization that hey, I need to do the test and engage in discussion with other colleagues and say, hey you need to do something to take a look.

Theme #2: I don't worry about it. As discussed under Theme #1, most of the participants admitted to not knowing much about prostate cancer but several participants also said that they do not worry about the disease. Participant F expressed that he believed that Afro-Caribbean men in general do not worry about prostate cancer for several reasons. First, he said that “probably because they don't know much about the disease and don't talk about it, and therefore they believe it is not a threat and will not happen to them.” In addition, he stated, “most of us don't fear what we don't know about.”

Participant H noted that he thinks that Afro-Caribbean men have the mentality that it's not going to happen to them. Based on that he said, “in general they are too laid back and take things too easy or are not as serious.” Participant H further expressed the opinion that Afro-Caribbean men don't take their medical health as seriously as they should. Two participants who did not know of anyone who had prostate cancer, contended that until the interview for this study, they were not aware of their susceptibility. Participant L further stated,

Now that I'm aware of it, it's something that's in my consciousness to get checked for. So I'm just looking forward to getting any additional information about how it would affect the community and stuff like that.

Participant M was one of the most informed about the disease but he commented that his interest and concern only started after his brother was diagnosed with prostate cancer about four years ago. He also emphasized that his general perspective on life is not to worry about things that you don't know are going to happen for sure because that can often be more counter-productive than doing the things you are supposed to do. He further stated that once you do what you are supposed to do, quite often things will turn out fine because you tend to get sicker from the stress than from anything else.

Participant M conveyed his thoughts relating to not worrying about prostate cancer:

I've never thought about it a whole lot until my brother was diagnosed with it and had prostate cancer surgery. Ever since then, about 4 or 5 years ago, my doctor did a prostate examination and told me that everything was fine. But before that, I never even thought or worried about it. I don't think about it much at all. Like I said, my brother was diagnosed with it. I don't think about it a whole lot and as long as I get tested and my doctor tells me that there is no problem, I figure there is no problem

Theme #3: If I got the disease, I would be concerned. Although many participants expressed that they were not worried about getting the disease, most of them expressed that they would have some level of concern if they were diagnosed with prostate cancer.

Several of them noted that their concern was mostly because they did not know a lot about the disease, how it would affect them, and possibly not having the proper medical support and finances to allow them to adequately manage the disease. Participant G noted that he read that there may be a number of false positives with the PSA test and although he was not sure what that meant, it was a concern for him.

The majority of participants stated that their main concerns related to what would happen to their immediate family financially if they were debilitated by or die from the disease. Participant K is married and his wife was diagnosed with breast cancer and had a mastectomy in her mid-forties. He conceded that after seeing what his wife went through he needed to be more concerned about his health in order to take care of his family. He subsequently had a colonoscopy which he previously was reluctant to do. He further stated that after our discussion he is now concerned about being diagnosed with prostate cancer and intends to have a prostate test in the upcoming year.

Participant G is 60 years old and maintained that because of his age, he did not have a personal concern. He noted however, that if he were younger, he would also be worried about other things associated with prostate function such as the ability to have sexual relations. That concern was also expressed by Participant J who felt that impotence should be a big concern for any man who is diagnosed with prostate cancer. Participant J was also concerned that the disease would be detected early enough to be treated successfully to prolong his life.

Participant M expressed the view that there are always concerns with any kind of medical problems and with prostate cancer. He stated that he knows there are many side-

effects and after-effects that someone can go through during treatment for any kind of cancer. However, he described why he would not be concerned about being diagnosed with prostate cancer:

I know of people who have had...let's say diabetes for 15 years and never knew. They go to the doctor and get diagnosed and then all of a sudden, they go downhill. It's like, now it's in your mind and you know you have this thing that you know can kill you if you don't treat it properly. You now have this additional stress that tends to do more to you as far as I can tell, than the actual disease itself. That's what it seems like anyway.

Participant F stated that his personal concerns relate to the fact that he doesn't know a lot about prostate cancer and what he could do, if anything to prevent it other than having yearly physical. Participant A expressed his views in the following manner:

The main concern is that people get into this situation and sometimes they don't have proper medical support, and sometimes they don't have the wherewithal or finances to avoid this situation. And then again, in Jamaica, not too many people have the money to start this regiment early on or make sure preventative measures are put in place. The basic thing is to get awareness and get the proper help early to prevent this being a chronic problem later on in life.

Theme #4: My family is important. One of the most frequently mentioned concerns and fears expressed by participants was how a diagnosis of prostate cancer would affect their families. Most participants described prostate cancer as physically and emotionally traumatic, but talked about the effect on their families as potentially

economically and emotionally devastating. Several participants talked about their experience dealing with the impact of having a family member go through managing some form of cancer. Participant K shared his experience and said, “I’ve had to go through breast cancer with my wife and that was pretty tough on the kids and the entire family so I’m sure it would be the same thing.”

A few participants talked about the role of the family structure within Afro-Caribbean communities. Participant D said he believed that his family would take care of him because “that’s the way we kind of live because if something happened to someone in the family, everybody comes together.” Similarly, Participant E communicated that apart from the “economic and intimacy issues,” it might bring his family closer. He stated,

I think that financially it would create problems even with regards to how you interact with your family...your wife, your kids. You might feel like you are not doing enough, because as a man, you tend to be the breadwinner, and if you cannot do that because you cannot work, it affects your family. All those things can be big issues and can affect your family life. Apart from the economic, the relationship with regards to intimacy might be an issue.” I would make sure I spend a lot more time with my family. I think it might make me get closer to my daughter and my wife given that it is something that can go any which way with regards to life expectancy. So in that way, I would make sure I spend a lot of time with my family.

Participant L contended that he thinks it would affect his family tremendously. He described that effect from a psychological, cultural, and economic perspective. He talked about the role of family within the village or parish structure in the Caribbean and the importance of the wife in “nudging” the husband to get tested. He said,

As a Caribbean man...or probably any man, first, there goes your manhood...it's damaged or hurt or something like that. That would possibly affect your mood and when your mood is affected, you get grumpy possibly affecting the wife and kids and there's a chance of you dying depending on how advanced the cancer is. So to me it's a big concern...and if the wife too is aware of testicular cancer, then the wife too will help put awareness or pressure on the husband to get tested because after all, she is part of the family and the husband needs to be nudged. The benefit is that his health and the health of the family. If you are not around, this is how your family will get affected, then they will jump on it to save the family. The Afro-Caribbean man grew up where the family is our support network...it's our village,...it's our everything,...it's our safety, and we want everybody to be healthy to make the village healthy.

Participant M felt that a prostate cancer diagnosis would be very traumatic for his family. He said,

I know it would put a lot of stress on them. It would probably put more stress on them than it would on me. Like I said, since my brother went through it and I know that, yeah, you can get through it you can get passed it, then I would do whatever is necessary to get through it. But in the meantime, my family would

worry about what if I don't get passed it or make it. In addition, cancer is always a big worry no matter what kind of cancer it is.

Although the majority of participants felt that prostate cancer would have a dramatic effect on their families, a few participants did not think it would affect their families in any significant way. Participant F expressed that it would not affect his family negatively because of a previous experience of prostate cancer within his family. As Participant F put it,

I do not think it would affect them negatively. I think it would cause some concern because anytime there is cancer in the family there is always some concern but I do not think it would affect them negatively because I've had a brother who had prostate cancer who lived with it for a number of years...I think it was probably 12-15 years before he eventually passed away, but I think in my family there is an awareness of prostate cancer because of my brother.

Participant G articulated that he was not sure about how a prostate cancer diagnosis would affect his family primarily because of prior similar experiences within the family. He stated that the experience of having parents in hospice and nursing homes would probably help them deal with such a situation. Similarly, Participant D was not sure about the effect on his family. Participant D stated,

Well, I don't know. Sometimes this world is so rough now you can't believe people will be there for you at all times because I know that I should be standing on three to four million dollars but because of the way I helped my family, I actually have nothing.

Themes #5: You can still live a long life if treated early. Most of the participants were optimistic about their chances of survival after a diagnosis of prostate cancer. The majority of participants also thought that if detected early and if one followed his physician's advice, the chances of survival were very good. This finding was contrary to the finding by Kleier (2004) who noted that Haitian men believed that once you had prostate cancer, the chance of survival was very small.

Despite the majority of interviewees not knowing a lot about the nature of the disease, symptoms, and testing, most of them were also aware that for men of African descent, testing at the age of 40 increases the likelihood of detecting the disease early and that increases the probability of survival. Participant B noted that, "if you deal with the disease in the right way, one could survive for very long time." That opinion was shared by Participant F who recalled that he knows a couple people who had prostate cancer for 15-20 years and they are still alive.

Participant I articulated that he could not speculate on a definite number of years one could survive because it depends on how determined that person is to be treated and how aggressive the treatment is. Participant K expressed similar thoughts by saying "I know that no matter what kind of cancer you get, if you don't treat it, or treat it early enough, your chance of survival is not very good." He continued by stating that "no matter what kind of cancer you get, if you discover it early, have it treated early, then your chance of survival is a lot greater."

One participant compared his chances of survival living in the United States versus living in the Caribbean. As he stated,

I think being in the United States and having an annual physical, I would tend to think that my chances of survival are very good because of the fact that it would be detected earlier and the kind of care I would get in the US. I would judge my chances of survival to be better than if I was living in the Caribbean. Therefore, I think my chances of survival would be good.

Participant D was not as optimistic as other participants. Based on his knowledge of a friend with prostate cancer, he communicated, “My buddy, he got diagnosed last year, about February and I can tell you that as we are speaking here, I don’t think he is doing too well.” Participant D stated that in his opinion, the length of time a man can survive after diagnosis is approximately two or three years. Participant E also conveyed that if the disease is too advanced, a couple years is likely. However, he also stated that if it is diagnosed early, 15-20 years is a possibility. He said,

I think that would depend on the stage you are in but I can see that if it’s too far along, maybe a couple years but basically if you caught it early, you could live a pretty decent life. I’m not exactly sure but maybe 20 years, 15 years or so.

Maybe something like that but I think it’s a matter of making sure that you keep monitoring maybe on a yearly or bi-yearly basis to make sure that nothing is going wrong. You can go back to your doctor if you had to. I think if you can do that and change your lifestyle to suit what is required to help you with prostate cancer, I think you can live a longer life.

The opinions of Participant L relating to survival were similar to those of Participant D. He stated,

Generally with cancer, the sooner you catch cancer the better. Obviously if you catch it in the beginning stages, you can have a long life. If you catch it in the middle stages then you can fight the battle. But if you catch it in the end stages, then your time may be limited. So when it comes to cancer, it depends on when and in which stage you catch it. Cancer is a thing you can live with depending on how soon you catch it.

Theme #6: Prostate cancer may affect my lifestyle. Dealing with any kind of cancer brings the topic of changes in lifestyle into discussion. Participants in this study were divided as to whether or not a prostate cancer diagnosis would affect their lifestyle. Participant I stated that it would affect his sexual lifestyle as well as his mental state while Participant M did not think it would affect his lifestyle much. Participant M expressed that he did not think there was anything that he currently does that he wouldn't still be able to do if he had prostate cancer and got it taken care of. According to him, "it's not as if I had a very physical lifestyle so I don't think it would affect my lifestyle much at all."

Many of the participants who knew or know someone with prostate cancer describe possible lifestyle changes based on the experience of that person with the disease. Participant D described his experience with his friend and stated,

The last time I went to say goodbye to my friend and saw the condition he was in with prostate cancer, I know it would affect me. When I see this guy go to the bathroom with blood coming from his penis. It's not easy to have a tube in your penis...you can't get up when you want and if you get over it, you have a bag on

your side. I see a couple of guys have a bag in their pocket or pinned onto their side.

Participant J described how it would possibly affect him because of his active lifestyle. He also described the financial effect on his family which would create a change in the lifestyle of his entire family. He said,

Tennis is my racket; I like to play tennis, so if as a result of being identified as having cancer, I would have to cut down on my tennis. Then it would be discouraging because I enjoy tennis as my physical outlet. So it all depends on the advice I get from the medical practitioner but at the present time I'm unable to speculate on 'what if' because I'm not sure. I've never really delved into what will happen if I get it because it's not something to which that I'm looking forward. So, at the sake of being repetitive, it's not something I have really ever investigated so it would depend on the advice of the medical practitioner so as a consequence, I'm not able to speculate how it would affect my family life. In the case of my brother- in-law he had some treatment in Sloan Kettering institute in New York. He was away from work for 6 or 8 months. When he went back to work, he was on a limited schedule and what he could lift, so if it were to happen to me and had to be away from work I guess it would kind of reduce the financial income. There would be some lifestyle changes. Those are some of the things I would immediately anticipate that I'd have to deal with at the time.

A few participants were unsure about how it would affect their current lifestyle.

Participant K expressed that he did not know about survival rates, management of the

recovery process after surgery, and how close one is to their original physical state. He said,

If it's one that is curable...I guess I don't know a whole lot about after surgery and the percentage of survival rate and recovery. When I recover if I'd be 100% back to normal. I don't have all that information to know if once treated I can just get right back and with monitoring and stuff like that, I can be just as normal. In addition, I am not sure if I'll be able to not think about it as if I'm dying if I play sports.

Participant L described the possible effect on his lifestyle from the perspective of what happens after the surgery and during the recovery period. He also expressed the feeling of being "less than a man," the resulting psychological impact, and the possible inability to do all of the things one is used to doing. He elaborated,

I think it would affect my lifestyle hugely. First there is the possibility of radiation, then there is the possibility maybe of losing the testicles and that would make you feel like half of a man. You would have to build up you confidence and consciousness about its ok to lose or it's a part of life but definitely it would affect who you are as a man. I come from a culture where you don't like to take or add anything from the body so the goal would be to catch it in the first place or the first signal but definitely it would affect who you are as a person.

Theme # 7: Start treatment early and follow the doctor's advice. Most participants emphasized that if prostate cancer was diagnosed in the early stages, their chances of survival would be very good. Even though the majority of participants were not familiar with the causes, symptoms and other signs of the disease, 12 (92.3%) acknowledged that they had taken some kind of, prostate cancer test, and 11 (84.6%) said they were likely to take either another test, or their first test within the next year (Table 2).

Several of the participants admitted to having either a DRE, a PSA, or both without being aware of what the tests were for, but expressed that because of the interviews for this study, they were now aware and would initiate having the tests in the upcoming year. Only one participant who is a nurse stated that he would not have a prostate test in the near future but he did not explain why.

Despite an apparent apathy about the disease as noted by the fact that several participant “were not worried” about getting prostate cancer, all participants expressed the importance and need to start management of the disease as soon as possible after diagnosis. In addition, they also expressed a high level of concern about how managing such a disease would affect their family and livelihood. Most of the participants were very emphatic about the need to follow medical advice if they were diagnosed because of their limited knowledge of the disease.

A few participants talked about seeking addition knowledge from the internet, or seeking a second opinion. Participant G noted that, “I’m not sure exactly what I would do except follow the recommendations of physicians.” He continued, “I would like to see

possibly multiple diagnoses opinions.” Participant H who is a nurse stated that he would need to do research about what options are available. He noted that “because of my medical knowledge, I know that if I have it, I am not going to fool around with it.”

Participant H continued,

If I should get prostate cancer, the first thing I want to know is, what are my options and where do I stand with things? What can we do to get rid of the problem? We know the problem is there, so how can we fix it? I would look at all the options I have and go with the best one. I would make sure that I research it properly first.

Several other participants emphasized the importance of enhancing their education and awareness as well as modifying their lifestyle. Participant E contended,

First I would make sure that I investigate the disease a lot more. I would go on the net to see what I can find about prostate cancer, what is required of someone who has prostate cancer, try to see what people do out there with regards to medication, with regards to dealing with their family. Just a myriad of things. It’s important to do that because I think if you don’t you’re going to leave yourself in the dark and always worrying about things. If you can open yourself to widening your scope of education with regards to prostate cancer, I think it can help you a lot more in dealing with the problem than if you don’t know as much and you always have at the back of your mind what’s going to happen down the road. I think if you prepare yourself and you know you need to change your eating habits, if you’re a smoker, you need to stop smoking....things like that and

change your lifestyle. Changing what you eat, what you drink, and things like that will go a long way in helping with the recovery process.

Similarly, Participant M shared,

First I would have to see what my doctor recommends and whatever he tells me.....you and also go on the internet and get volumes of information about what you can or can't do and try to sift out the best of those in conjunction with what the doctor tells you to do. I trust my doctor and that's why I stay with him. If surgery is the first step, then for me, that's the first step because this is something you want to take care of if you get it as soon as possible rather than sitting down and waiting for a few years to decide what to do.

A few interviewees described other options that they thought would be useful in managing the disease in addition to taking their physician's advice. Several participants discussed the importance of diet and talked about specific plants and herbs that they felt would be beneficial for someone with prostate cancer. According to Participant I:

Yes, I believe that modifying diet and lifestyle will have a positive effect on prostate cancer. I would deal with it in natural terms and foods that are anti-prostate. You have to eat the right kind of food. Some foods that are committed for the prostate are tomato, cabbage, broccoli, and cauliflower, and there are other foods too but these are the main foods. So I recommend for all Afro Caribbean men, for all men for that matter to do so for their prostate, to eat healthy and get a regular checkup after age 25. Get your regular checkup.

I would take some more, very aggressive steps, double up, or triple up or quadruple up on my pills, my Saw Palmetto, my pumpkin seed oil and the other pills that I am taking and now getting into taking vegetable, my tomato, broccoli, cauliflower and cabbage and I would research more to see what is out there to beat the cancer. I would be a lot more aggressive in my research and my eating style.

Participant A expressed similar views about plants that would shrink the prostate and would possibly be useful for prostate cancer. He stated,

You may have heard that there is a doctor who came up with research about a particular plant which is known to shrink enlarged or inflamed prostates. The plant...and you can look this up.... is called guinea hen weed. There is another plant called the marble ball which is similar to the guinea hen weed that is grown all over the Caribbean...but people do not know about it. Those two plants have been researched and known to shrink the prostate and may be good for prostate cancer as well.

Participant D stated that he believed that “bush medicine” could be helpful for prostate issues, but he was no longer sure after he saw the condition of one of his friends who believed in the local practices. As he expressed it:

Before I come here the last time, I went to say goodbye to my friend and the condition I have seen my friend in with prostate cancer, I know it would affect me. When I see this guy go to the bathroom with blood coming from his penis and thing. That would be the last stage. He still don't want to take the operation.

He's a guy who used to believe in bush medicine back home. They say that good for it and I was thinking that but low and behold, he come down with this thing so rapid and I strongly believe that if he were going to take a test, even once a year, it would not have cut him down so fast. Based on the condition I see my friend in, I know it would have an effect on my life. It's not easy to have a tube in your penis; you can't get up when you want and if you get over it, you have a bag on your side. I see a couple of guys have a bag in their pocket or pinned onto their side.

Theme # 8: Finance and health insurance can be burdens. Ninety two percent of participants in this study reported receiving either a DRE, a PSA, or both tests.

Despite the relatively high percentage of current study participants that were tested within the last two years, some of their views on why many Afro-Caribbean men are reluctant to get tested for prostate cancer were similar to those found in the Parchment (2004) study. In the Parchment (2004) study, 80% of study participants stated that one of the main reasons why they avoided early detection screening was a dislike for the DRE. Several study participants stated that finance or lack of insurance is a problem if you do not have work-sponsored health insurance. This finding was similar to that of Lee et al. (2012) who determined that African American participants who had difficulty accessing quality health care were unlikely to have a prostate cancer test.

As participant H described it,

In general, part of it is the financial aspect of that stuff. A lot of Afro-Caribbean men might not have the financial resources, insurance, and the job. This is the

biggest drawback at times. A lot of times people have to work more than one job...the time factor of finding the time. I do believe that those are some of the main stuff that causes the problem, finances and having to work so much.

Participant A shared similar thoughts and also talked about the importance of awareness. As he described it,

Health insurance is probably the biggest impediment for Caribbean people who may want to have this on an annual basis...and awareness. Awareness in terms of education of the ramification of what prostate cancer is, what it will do to you in the future because if you are an active person and this thing affects you and get worst, you cannot do anything....you become an invalid and a problem to everybody around you.

Participant L was more descriptive of some of the cultural and psychological issues that may play a part in the reluctance to test. He said,

Well, there is probably the stigma of the whole anal intrusion in the culture. But with the anal intrusion, I think if you come up with the idea that this may help you, then they will be more likely to get tested. They may not mind the anal intrusion if it's going to help them and their family in the long run. So that's how the Caribbean men will be more likely to get tested. The benefit is his health and the health of the family.

Themes Associated With Research Question #3

For Research Question #3, I sought to answer the following: “To what extent, if any, does culture affect the lived experiences, beliefs, and motivation to act relative to

prostate cancer for Afro-Caribbean men?” I asked participants several different questions that were meant to address Research Question # 3. Only two themes were identified as appropriately addressing Research Question #3. Those themes were: there is a stigma with the anal stuff, and that’s the way it is done back home.

There is significant scientific evidence that cultural practices affect an individual’s behavior as it relates to promoting, maintaining, and restoring health. Culture also affects how, when, and with whom individuals seek help for prevention and treatment of various conditions and diseases (Roux & Halstead, 2009). For individuals from different cultures who are immersed in the health care system of the dominant culture, confounding variables of culture, race, ethnicity, and socio-economic factors impact how they make health management decisions.

The attitudes towards prostate cancer of Afro-Caribbean men who have immigrated to the United States may be strongly influenced by heritage consistency and health traditions, as well as cultural phenomena that affect their health. The concept of heritage consistency implies that the more a person identifies with their traditional heritage, the more likely they will keep their ethnocultural traditional health beliefs and practices (Spector, 2002).

Prostate cancer testing or screening can be viewed as preventative care and the emphasis on preventative care is greater in the United States than in most developing regions such as the Caribbean. It was therefore important to investigate how much the cultural influence still permeates the health care thinking and health protocols of Afro-

Caribbean men who have resided in the United States with their families for greater than 10 years.

Theme #1: There is a stigma with the anal stuff. Most of the issues discussed by participants that were assessed to be culturally influenced or motivated related to their reluctance to get a DRE. For several participants, that was the main reason why they would not initiate any conversation regarding testing for prostate cancer with their physician. Two participants from Jamaica were particularly adamant about their hesitancy relating to having a man do anything that involved their rectum or touching their genitals because they associated those actions with homosexuality.

Participant E said,

I think that it is cultural and as Afro-Caribbean men, we look at ourselves as macho, or maybe a little more like nothing is going to happen to us.

I think that's a big thing with Caribbean men. The other issue or cultural part of it is that it has something to do with the rectum. I don't think Caribbean men are big on that stuff. Unless they change the culture of thinking and behavior, they will continue with a prostate problem. Jamaica has a big percentage of men, all the Caribbean region I believe, who are victims of the prostate behavior.

Similarly, Participant L conveyed:

There is probably the stigma of the whole anal intrusion in the culture. Caribbean men will be more likely to be put off by the anal intrusion stuff but if shown the benefit, they will be more likely not to mind.

Theme #2: That's the way it is done back home. Several participants talked about the influence of their culture on their perception and beliefs about prostate cancer. In many cases, those beliefs and perceptions were expressed in terms of “the way it is done back home.” None of the participants talked about the cultural beliefs in terms of those beliefs having a big influence on how they now think about prostate cancer. In discussing why people don't worry about prostate cancer, Participant M stated, “I think it's the way we grew up.” “People figure that if they don't know about it, then it isn't a problem.”

One participant talked about how a few people from his Island believe that prostate cancer is a result of “Obeah” or poison. Obeah is a term used in the West Indies to refer to folk magic, sorcery, and religious practices derived from West African origin (Mantz, 2007). Participant A was emphatic that he no longer believes that Obeah or poison are the causes but expressed it in this fashion:

And so, you often hear that somebody obeah them or somebody poison them when they really had something severe they could have prevented if they were doing annual physical check-ups. As I've grown up, I've come to realize that it was not obeah or poison. The experience with cancer was not as well-known as it is now but still some people think obeah or poison may be the problem but still there is more awareness of what's going on.

Participant L described the difference between an encounter with a physician in the United States and one in Jamaica. He stated,

I think doctors in the US today expect patients to come to them with the problem. So, being in America, I need to adopt the mentality that I have to take it upon myself and say, “Hey I want to get tested for the anal disease.... I want to get tested for this or that.” I find that when I go to a male or female doctor, I believe that my services are less with a male doctor. So for me, I find that I need to be conscious medically about getting tested for this or that because when I go to the doctor’s office, he only has about 10 minutes, so if you don’t put your thing on the table, he’s not going to be thinking about it. So your health is in your hand. I come from a culture where you don’t like to take or add anything to the body so the goal is to catch it at the first signal.

Participant L also talked about the difference in the likelihood of surviving if one is diagnosed and treated in the Caribbean versus being in the United States. Although that is not related to a cultural impact, it speaks to the availability and difference in resources. Participant L stated:

I would tend to think that my chances of survival are very good because of the fact that it would be detected earlier and the kind of care I would get in the United States. I would judge my chances of survival to be better than if I was living in the Caribbean.

Summary

In an attempt to get a better understanding of the perceptions, attitudes, and experiences of Afro-Caribbean men, I conducted a qualitative phenomenological study where I held in-depth face-to-face interviews with 13 Afro-Caribbean men who have resided in the United States for 10 years or greater. The interviews and questions formulated and asked were attempted to answer the three research questions outlined in this paper:

The findings relating to those research questions were summarized in Chapter 4. In addition to outlining the research questions in Chapter 4, I also reviewed the sampling logic, the sampling population, the data collection process, the demographic profile of participants, the research questions, the data analysis process, tools and findings, the presentation of themes that addressed each research question, and evidence of trustworthiness. In addition, summaries and synopses of the in-depth interviews were incorporated into the results.

The interviews provided a myriad of significant statements and opinions. The majority of those statements and opinions that related to the research questions were selected and placed under each appropriate research question. In the early stages of the data analysis process, I identified and extracted statements based on the questions asked. I used NVivo 10 to facilitate the creation of 21 nodes, their sources, and the number of times these nodes were referenced by each participant. Although the nodes were created based on responses to each question, only those that were from three or more sources and referenced a minimum of 6 times were deemed to be important contributors to the data

analysis. A total of 13 different themes were selected that addressed the three research questions.

Three different themes were identified as addressing Research Question #1. The themes noted were: Awareness and education have a lot to do with it, it's a matter of attitude, and if something is wrong, my doctor will tell me. Eight different themes emerged that addressed Research Question #2 and those were: I know very little about the disease, I don't worry about it, if I got the disease I would be concerned, my family is important, you can still live a long live if treated early, prostate cancer may affect my lifestyle, start treatment early and follow the doctor's advice, and finance and health insurance can be burdens. In addressing Research Question #3, only two prominent themes were evident: There is the stigma of the anal stuff, and that's the way it is done back home.

Transition Statement

In Chapter 5, I present a discussion and evaluation of the research findings deliberated in Chapter 4. I also discuss the limitations of the study, implications for social change in health management and policy, and recommendations for future research.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative, phenomenological study was to explore and analyze beliefs about prostate cancer in a sample of Afro-Caribbean men between the ages of 40 and 75 years old who reside in the United States. The objective of the phenomenological approach was to determine what an experience means for the persons involved and their ability to provide a comprehensive description of that experience or perception (Moustakas, 1994). Chapter 5 provides the interpretation of the findings and conclusions based on the data results in Chapter 4.

There are several reasons why this study was deemed as being important. First, according to researchers such as Nanton and Dale (2011) and Kleier (2003, 2004), Afro-Caribbean men are poorly represented in cancer research literature in the United States and the United Kingdom. In addition, Peterson et al. (2004) argued that of the few qualitative prostate cancer studies of Afro-Caribbean men conducted in the United States, most have involved participants from only two or three Caribbean countries. This was exemplified by the Kleier (2003) study that only involved men from the islands of Jamaica and Haiti.

Interpretation of the Findings

In analyzing the findings of this study, I identified 13 themes that addressed the three research questions.

Answers to Research Question #1

The three themes that were found to address Research Question #1, “What are the lived experiences of Afro-Caribbean men relative to prostate cancer?” revealed that participants did not have personal experiences dealing with prostate cancer.

Consequently, the information they shared was based on hearsay, the experience of someone they know, and their perception of how the disease would affect them. There was a significant overlap between the several of the themes associated between to Research Question #1 and Research Question #2. Several responses relating to “lived experiences” and “perceptions of risk, risk factors, and treatment” centered on lack of awareness, lack of education, attitude, knowing very little about the disease, and not worrying about it.

Participants acknowledged that their approach to screening and management of the disease was influenced by their attitudes towards prostate cancer, and those attitudes were influenced by their lack of awareness and education about the disease. The apparent negative attitude towards screening seemed consistent with findings by Parchment (2004) who found that as many as 80% of Afro-Caribbean and African American men listed that they did not undertake screening because of dislike of the DRE. Lee et al. (2012) determined that men who had difficulty accessing quality healthcare were less likely to have a PSA test. Participants in this study reported a very high rate of screening (92.3%), and although they were not asked about their healthcare access, all of them had a physical exam within the last 1 to 2 years. It is possible that the high rate of

testing pointed to an association between access to healthcare and probability of getting tested as noted by Lee et al.

Two overriding themes that evolved in response to Research Questions #1 and #2 were the lack of disease awareness and education among this study group and all participants expressed the importance of increasing their level of awareness and education about the disease. They seemed to associate lack of awareness with their apathy and not being worried about the disease. Several participants specifically stated that once information about prostate cancer is brought to their attention, it would be in their consciousness. They also admitted that their attitude was changed or modified because of the discussion associated with the interviews for this research and the increased awareness the discussion brought about. Conversely, Magnus (2004) found that prostate cancer knowledge seemed adequate among multi-ethnic Black men in Miami and Fort Lauderdale, Florida. Even though the men in the Magnus (2004) and Allen et al. (2007) studies were not all of Afro-Caribbean origin, there is not enough available comparable data on prostate cancer and Afro-Caribbean men given the limited number of qualitative studies previously conducted.

The majority of participants posited that they relied on their physicians to initiate the discussion about prostate cancer and related screening and assumed that if there was any possibility of them having prostate cancer, their physician would tell them. The level of trust participants expressed for their doctors was clear. This was an interesting finding because distrust of the medical system was a major reason given by Blacks in several studies (Ferrante et al., 2011).

Despite stating that physician advice was a significant determinant in screening behavior, as many as 72% of all African American men in the Steele et al. (2000) study said that their physician never discussed prostate cancer testing with them. Parchment (2004) also noted that 75% of men in his study were not referred to screening by their physician. Allen et al. (2007) demonstrated that African-American men expressed frustration because they perceived it as difficult to get information on the disease, particularly from their medical provider.

Answers to Research Question #2

According to Moustakas (1994), perception is regarded as the primary source of knowledge, and it opens a window unto things (pp. 53-54). The eight themes that emerged in addressing Research Question #2, “What are the perceptions of risk, risk factors, prevention, detection, and treatment of prostate cancer?” revealed that men did not know very much about the disease and did not worry about having prostate cancer.

Based on responses, it was very evident from the early stages of the interview process that most participants knew very little about prostate cancer. That seemed to support findings from several studies of men of African descent. Researchers such as Ben-Shlomo et al. (2008) postulated that initial suspicion of a prostate problem in that group may have been related to presentation with symptoms rather than through a proactive prostate cancer test. Rajbabu et al. (2007) found that Afro-Caribbean men had poorer knowledge of prostate cancer than White men, and this finding was consistent with qualitative studies conducted in the United States by researchers such as Allen et al. (2007) and Ross et al. (2008).

Kleier (2004) found that men in the Jamaican cohort of her research were aware of the signs and symptoms and knew of risk factors for prostate cancer even though they were not aware of the signs and symptoms. However, the Kleier finding is inconsistent with the findings in this study where most Afro-Caribbean men knew very little about prostate cancer, risk factors, and signs and symptoms of the disease.

Although most participants in this study stated that were not worried about prostate cancer, the majority of them also expressed that if they were diagnosed with the disease, they would have some level of concern, particularly as their condition would affect their families. Many participants expressed that they would not object to any form of testing once they knew what it was for. This was a result of their fear of getting prostate cancer and the resulting consequences and was a validation of using the HRM and TRA models. They were emphatic about the importance of family and the economic and emotional burden it would place on their loved ones. Most participants stated that they were sure their family would take care of them because “that’s the way we kind of live.” In addition, they were concerned that having prostate cancer would affect not only their lifestyle but that of their family as well. In searching for data that looked at how Afro-Caribbean men assessed the impact on family and lifestyle, there was little comparative qualitative information, and so these findings shed some light on those issues.

Despite the low awareness, the majority of participants thought that if the disease was caught early, they would have a good chance of living a long life after diagnosis. This was unlike the results of a study by Demark-Wahnefried et al. (1995) who found

that African-American males did not believe that men with prostate cancer can lead normal lives or that men can be symptom-free but yet have prostate cancer. Although over 93% of participants in this study stated that they had received a test for prostate cancer, several participants conceded that they were not even aware of what the test was for at that time. For the seven (53.8%) who received a PSA test, only two were told or made aware of what the results of the tests were and what the corresponding number meant. Nanton and Dale (2011) also found that 16 of 17 Afro-Caribbean men in their U.K. study did not recall getting any information on the disease, treatment, and side effects even at the time of their diagnosis.

Participants in the Haitian cohort of the Kleier (2004) study believed that having prostate cancer would result in death and chances of survival beyond 2 to 3 years was minimal. Most participants also emphasized the importance of starting treatment early, trusting the doctor, and following the doctor's advice. However, according to Thompson et al. (2008), many African-American men generally do not have an ongoing relationship with a primary care physician, and contact is more likely to be a consequence of a late-stage cancer diagnosis.

It was obvious during the interviews that most participants did not know the specific age for starting testing in Afro-Caribbean men, but 92.3% stated that Afro-Caribbean men should be tested as early as 40 years old. I found such a view to be surprising given that the generally publicized age for screening is 50 years of age, and 40 years of age is more aggressive than the American Cancer Society's guidelines for the

early detection of cancer, which recommends that men of African descent should begin testing at age 45.

Answers to Research Question #3

The influence of variables such as culture, past experiences, and motivation on personal perceptions can have an indirect effect on whether or not a person chooses to modify their existing behavior (Hayden, 2009). Culture also affects how, when, and with whom individuals seek help for prevention and treatment of various conditions and diseases (Roux & Halstead, 2009).

Only two themes were identified as addressing Research Question #3: “To what extent, if any, does culture affect the lived experiences, beliefs, and motivation to act relative to prostate cancer for Afro-Caribbean men?” Similar to findings in studies by Kleier (2003) and Parchment (2004), the majority of men in this study contended that there was a cultural stigma connected with the DRE, the likelihood of a man inserting a finger in their anus, and the association with homosexuality. That was particularly evident in comments from participants from Jamaica. However, all participants said that once they are made aware of what the test was for, they would not be averse to having it done.

At the onset of this study, it was presumed that culture would play a significant part in how Afro-Caribbean men perceived prostate cancer. However, one of the most surprising findings was the minimal role culture seemed to play in how Afro-Caribbean men think about the disease. According to Roux and Halstead (2009), cultural practices

affect how an individual relates to health behavior as well as affecting how, when, and with whom they seek help for prevention and treatment.

For individuals immersed in a dominant culture, confounding variables such as culture, race, ethnicity, and socioeconomic factors impact how such peoples perceive their susceptibility, severity, benefits, and barriers to healthcare (Bandura, 1982). It seems that the findings regarding cultural impact for these participants support Bandura's (1982) assertion. This was a noteworthy finding because the attitudes towards prostate cancer of Afro-Caribbean men who have immigrated to the United States may be strongly influenced by heritage consistency, which implies that the more a person identifies with their traditional heritage, the more likely he or she will keep ethnocultural traditional health beliefs and practices (Spector, 2002).

One of the reasons for requiring a minimum U.S. residency of 10 years for participants in the current study was an attempt to minimize the effect of culture on responses. Prior to the results of this research, one might presume that Afro-Caribbean men may be heritage consistent, but the findings indicated that they are mainly heritage inconsistent and identified with the health beliefs and practices of the dominant U.S. culture. It is possible that the amount of time residing in the dominant culture impacted the findings relating to culture. The other theme that emerged was associated with talking about how things are done back home regarding testing and treatment. A few participants discussed the way some people in the Caribbean perceive how someone gets prostate cancer, how to get rid of it, and why they do not worry about getting the disease. Most participants expressed that they would be taken care of by family if they got

prostate cancer. One participant stated, “Within our culture, that’s the way we kind of live because if something happened to someone in the family, everybody comes together.”

Significance of the Study

A comprehensive literature search on prostate cancer in Afro-Caribbean men in the United States revealed that only a few studies have documented and discussed how these men view this potentially fatal disease and their susceptibility to it. Of the few qualitative studies where the focus was on Afro-Caribbean men in the United States (Kleier, 2003; Lee et al., 2012; Magnus, 2004; Parchment, 2004), most researchers did not assess the views and perceptions of study participants.

Men of African descent, particularly African American males, have been found to have a higher risk, higher mortality, and higher incidence, and are likely to be diagnosed with prostate cancer at an earlier age than men of any other race (Jemal et al., 2010). Studies such as Allen et al. (2007) have documented that awareness of the disease, its risk factors, and the role of screening among African American men is minimal. Several qualitative studies have been conducted on prostate cancer and African American males, but although Afro-Caribbean and African American men share common ancestry, one cannot presume that the views and perspectives will be similar because of cultural differences and other factors.

This study sought to fill the gap in the sparse body of qualitative literature that represents the perspectives of Afro-Caribbean men and prostate cancer. The findings support several previous findings of Afro-Caribbean and African American men’s

perspectives relative to prostate cancer. Findings such as low levels of disease awareness and education, a general apathy towards the disease, the issues of finance and health insurance that affect testing and “going to the doctor,” the reliance on their physician for PC information, and the reluctance to get tested because of the DRE (Kleier, 2004; Pedersen et al., 2012) are consistent with findings from the previously mentioned studies.

However, several of the findings from this study also contradict previous findings. For example, Magnus (2004) noted that one of the variables that positively correlated with prostate cancer knowledge was the level of education. The findings in this study relating to knowledge of prostate cancer, its symptoms, and side effects was interesting given that the average years of school for this group was approximately 16 years, which equates to at an average of 4 years of college. This may be significant because if prostate cancer knowledge is positively correlated with education, there is a great opportunity to reach this group with a variety of published or marketed awareness information. Unlike men in the Thompson et al. (2008) study, the majority of men in this study have an ongoing relationship with their physician. That finding is also potentially significant because men in this study noted that physicians are their main source of prostate cancer information and primary care physicians and their offices or clinics present great potential media for reaching this group.

Demark-Wahnefried et al. (1995) found that African-American men did not believe that men with PC can lead normal lives. Kleier (2004) assessed that in the Haitian cohort of her study, participants believed that treatment was painful, equated having the disease with death, and treatment would be ineffective. Those findings were

not consistent with the findings in this study as most men (92.3%) strongly felt that they could live long healthy lives after diagnosis and treatment. That is a significant finding because it seems to suggest that Afro-Caribbean men may be eager and willing to be aggressive because of their positive outcome outlook.

Apart from a study by Bunker et al. (2002) where more than 50% of men aged 40-79 on the Island of Tobago were screened for prostate cancer, there are not many data on the percentage of Afro-Caribbean men that were screened for the disease. One study by Pedersen (2012) contended that only 5% of Black Caribbean men in the United Kingdom had been tested for prostate cancer. One other study in Jamaica by Hutchinson and Simon (as cited by Kleier, 2003) noted that 34% of Jamaicans said they had an annual check-up but did not include age or sex of the participants. The percentage of men in this study who were tested for prostate cancer was 92.3%. It was surprising and significant to discover such a high percentage of Afro-Caribbean participants received a test for prostate cancer because according to Hennis et al (2011), specific data on the percentage of Afro-Caribbean men that undergo PSA and/or DRE screening is lacking. It seems to suggest that screening among Afro-Caribbean men is not necessarily such a fearful thing if they are aware of what the test is for and should give optimism to clinicians and health care professionals who need to target this group.

As discussed previously in this paper, there is a significant gap in the research about Afro-Caribbean men and prostate cancer. Of the few studies identified, only men from a few Caribbean territories were researched. This body of research supports some of the previous findings, but it also has found data that contradicts those findings as well.

Issues such as the lack of awareness, negative attitude toward screening, low knowledge of the disease and its symptoms, and apathy towards the disease have been found in the limited previous studies. However, new issues were discovered such as the high level of trust participants placed in their physicians, the emphasis on family as a means of support, the positive outlook on outcomes if treated early, and the low impact of culture on beliefs are some of the main themes that emerged in this study.

Even though there are several similar findings, what is most significant about this research is the addition to the existing meagre body of qualitative work for this group. In addition, there were 13 participants from seven territories. While I do not suggest that even such a more representative group is truly representative of the region, it gives a broader perspective given the limited scope that a qualitative phenomenological study allows. In this study, I am able to therefore provide informed documentation from the broadest group of Afro-Caribbean men and their perceptions, experiences, and beliefs about prostate cancer. I am further able to highlight the low level of education and awareness of the disease and the need for educational and promotional efforts targeted to this group. However, I believe that additional research needs to be done to determine if increased awareness and education of this disease would actually lead to increased dialog, testing, and treatment in this high-risk population.

Conceptual Framework and Implications

The findings regarding dislike of the DRE were clearly communicated. Despite stating that they were not worried about prostate cancer, participants conveyed concerns and fears if they got the disease, and stated that they would be willing to get the DRE or

other screening procedures once they knew what it was for, and what early diagnosis meant for their chances of survival.

Proponents of the TRA suggest that people will choose to engage in behaviors that are likely to result in desirable outcomes considering the consequences of the alternatives. The findings also demonstrate the application of the HBM for this study because the participants demonstrated that they were willing to change or modify their behaviors based on their perception of the severity the disease, their susceptibility and risk to prostate cancer, and the benefits from early diagnosis and treatment.

The synthesis of the HBM and the TRA was based on the notion that behavior depends on the value people place on outcomes, and their assessment of the probability that a given action will result in that outcome (Poss, 2001). As noted previously, the TRA was combined with the HBM because it is purported to account for the cultural factors which the HBM does not and are implicit in this study.

I assert that the synthesized conceptual framework was an appropriate choice of framework for this research and correlated well with the findings. The results were consistent with the framework because participants clearly placed a high value on survival as a positive outcome associated with getting tested and early treatment. In addition, most participants also assessed that testing and early treatment would result in a high probability of survival and along life.

Limitations of the Study

There were several limitations associated with this study. First, as the sole researcher, I interviewed participants, gathered data, attempted to make sense of it, and

organized it into themes. To increase credibility, I used member-checking with eight of the participants who were willing to review the transcribed data. Member-checking also gave participants the opportunity to correct errors and dispute what they perceived as misinterpretations. In addition, member-checking afforded participants the opportunity to volunteer additional information which may have been stimulated by reading the transcribed information. Five of the participants were not interested in member-checking despite my request. Although this is a threat to validity, they indicated that they did not have the time to do so. Only two of the eight participants who member-checked the transcripts of their interviews made any changes, and those were grammatical rather than content modifications. It is unavoidable that despite using member-checking as a form of triangulation, there is always the possibility of researcher bias. However, even though I was only able to get eight out of 13 participants to member-check their responses, I am confident that interviews were transcribed verbatim and those perceptions were captured in the results and analysis

Four (30.8%) of the participants are part of a summer cricket league of which I also participate. That is an important limitation because of the potential for researcher influence during the interview process. I specifically outlined that relationship in Chapters 1 and 3 and during the data collection process, I consciously attempted to make sure that I did not influence the answers provided, and outlined those specifics under “Evidence of Trustworthiness” that will be discussed later in Chapter 5.

Another important limitation of this research related to the fact that the Caribbean region is made up of over 40 different territories with educational and cultural beliefs that

vary from territory to territory. Categorizing people from the Caribbean region as a single group is problematic and does not allow for those differences. Furthermore, availability and access to health care services vary from island to island, and may affect how Afro-Caribbean U.S. immigrants access those services once they are living in the United States.

Small sample size is one other important limitation because it can create questions relating to the quality and credibility of the findings, as well as the trustworthiness of the researcher. Findings therefore tend to be subjective, not replicable, and should not be generalized unless the quality of the research meets certain criteria as defined by the reader. However, Patton (2002) pointed out that whether sample size is adequate or not depends on peer review, consensual validation, and judgment.

Evidence of Trustworthiness

Credibility (Internal Validity)

The validity of this study is highly dependent on the authenticity of each participant's response. In an attempt to minimize any biases related to the responses, I attempted to abstain from participating in the conversations when participants were providing their answers. I also refrained from providing positive or negative feedback during the course of the interviews. In addition, I did not provide my personal opinions or biases relating to their ideas, thoughts, and opinions. I encouraged participants to speak freely and openly, even if they thought their opinions might not be mainstream or popular. I also encouraged participants to speak as someone who is a resident of the United States, rather than

speaking from the perspective of how the questions would apply to someone living in the Caribbean.

According to Maxwell (2005), as the qualitative researcher, I can affect the findings because of my personal perspectives and experiences. As a form of triangulation and in an effort to ensure what I heard, recoded, and transcribed was consistent with what they said and meant, 8 participants agreed to member-check the transcribed data. According to Guba (as cited by Creswell, 2008), member-checking is viewed as the most critical technique for establishing credibility. I emailed the transcribed information to only eight of the thirteen participants because I did not have access to the email address of the others and they were unwilling to review their transcribed data. I received responses from seven of the emailed participants who were all satisfied with the information as transcribed.

Transferability

Although the views of such a small purposively selected group cannot be generalized to Afro-Caribbean men in general, the findings may be transferable if the reader is satisfied that background material, such as demographics and study setting provide a context that allows the reader to decide for which situations the findings might provide valid information (Malterud, 2001).

External validity is the degree to which findings can be generalized or transferred, and sample size is one significant compromising factor (Creswell, 2012). Creswell posited that the intent of qualitative research is not to generalize findings to individuals outside of those under study (Creswell, 2012). Patton (2002) emphasized that “the

validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capability of the researcher than with sample size” (p. 245).

The purposive sampling strategy used in this study was intended to include participants from as many English-speaking Caribbean islands as possible with the desire for extrapolation in mind (Patton, 2002). With the hope of some transferability in mind, I provided background material, such as demographics and study setting to provide context so that the reader can decide for which situations the findings might provide valid information (Malterud, 2001). Therefore, the design of this study, the assumptions of the research questions, and the reasons for the sampling strategy were made clear so that they might provide an indication of what an adequate degree of transferability could possibly be for the reader (Malterud, 2001).

Dependability

Dependability for this study was enhanced with the use of two good quality audio recording devices and the detailed and exact recording of the interview data. As noted earlier, member checking was employed to ensure accuracy of transcription. Eight participants agreed to member-check the data and the few changes they wanted made were grammatical and not content changes.

Confirmability

I attempted to avoid leading questions. However, based on the responses, I needed to follow-up with additional questions to enhance clarity and consequently, a few questions were directly related to the previous or preceding ones.

Recommendations

Based on the answers and themes that resulted from the questions asked in this study, it was apparent that there is a low level of education and awareness among Afro-Caribbean men despite the study group having an average education level equivalent to four years of college. This was not a surprising finding based on the few studies of Afro-Caribbean men that had been conducted (Kleier 2003; 2004). However, it was surprising given the correlation found between education and prostate cancer knowledge in multi-ethnic Black men in Florida (Magnus, 2004). In addition, there was apathy and lack of concern about getting prostate cancer despite being in the highest risk category for getting the disease earlier, being at a more advanced stage when diagnosed, and having a greater probability of dying from the disease. Those findings speak to the need for increased awareness and educational efforts specifically targeted to this population. In the African American prostate cancer studies, participants were recruited and accessed through churches and barber shops. Reaching the Afro-Caribbean community in the United States may be harder as members of this community tended to be more dispersed and less likely to congregate in specific locations or businesses. It would therefore be important to create educational pieces that are specifically targeted to the Afro-Caribbean community as well as determining the most effective way to get the information to the target audience. Such pieces could be in the form of pamphlets that highlight the symptoms and consequences of prostate cancer and flyers that encourage talking to their physicians about prostate cancer and screening. These educational pieces can be

distributed at various events that Caribbean people frequent and targeted to various Caribbean organizations.

Despite the apathy and lack of concern about the disease, participants expressed a high level of concern if they were diagnosed with the disease. The synthesis of HBM and TRA helps in explaining this dilemma because some theorists believe that in order to facilitate a change in behavior, a person needs to have the knowledge and wherewithal to manage that behavior and also believe that they have the ability to practice the new behavior. In this situation, the lack of concern was determined to be a consequence of lack of knowledge and awareness. Once they acquired the knowledge about the disease and its consequences, or are diagnosed with the disease, they are highly motivated to take action. In this study, participants believed that testing and early treatment provides them with the wherewithal to manage prostate cancer.

Participants' concerns were strongly discussed in terms of how the disease would affect their families. Participants also were emphatic about the importance of family in their existence. In terms of increasing awareness, one recommendation would be to get the information into the hands of the wives or significant others. In addition, given that most study participants relied on their physicians for prostate cancer information, any information targeted to this group should also strongly encourage them to initiate a discussion on prostate issues with their physician.

Information and fear of the consequences from getting the disease were noted as strong motivators for testing and treatment if diagnosed. In fact, several participants who had been tested but were not clear about what the tests meant, conveyed that they will be

pro-active about testing within the next 6 months or 1 year. Information targeted to this population therefore needs to not only contain information on what prostate cancer is, risk factors, and treatment, but explicit information about the consequences of not getting tested or not being diagnosed early. Based on the findings from this study, I contend that Afro-Caribbean men are willing to modify their attitudes about emotional issues such as the DRE and general prostate cancer screening, as well as visiting their physician on an annual basis once they are aware of the consequences of having the disease.

Recommendations for Future Research

In a critical review of studies on migration and prostate cancer, Angwafo (1998) concluded that there needs to be additional international and cross-cultural epidemiologic studies to investigate the incidence, knowledge, and perceptions of prostate cancer in ethnic populations. Kleier (2003) conducted a literature review that looked at prostate cancer in Black men of African descent and concluded that prostate cancer interventions developed for African-American men may not be effective for Afro-Caribbean men. One qualitative study conducted by Nanton and Dale (2011) investigated the perceptions and experiences regarding treatment and care of Afro-Caribbean men in the United Kingdom relative to prostate cancer, but prior to this study, no similar studies have been conducted in the United States.

The current study suggests several insights into the perspectives, experiences and beliefs of Afro-Caribbean men relative to prostate cancer. However, as discussed in the limitations section, a sample of one to three participants from each island provides a very limited view. Additional information may be gleaned if a broader mixed-methods study

is conducted in a major metropolitan city such as New York or Atlanta. Such a study should survey and interview at least four men from each territory using purposeful sampling, and including variables such as educational attainment and income levels.

In addition, it is generally presumed that Afro-Caribbean and African American men share similar perspectives and beliefs about prostate cancer. Although this study touches on some of the differences between the African American and Afro-Caribbean perspectives, a comparative study of Afro-Caribbean, African American, and African men who all reside in the United States would provide valuable information on how this broad high-risk group actually think about this potentially killer disease. It would be also valuable if such a comparative study included men from diverse economic, social, and educational backgrounds.

Recommendations for Practice

Based on findings by Pedersen et al. (2012), there have been limited efforts to ensure that Afro-Caribbean men have access to relevant disease information. Four of the most significant findings from a practice perspective were: the trust Afro-Caribbean men have in their physician, the fact that they get physical exams every one or two years, the percentage of them that have had a prostate screening, and the fact that the majority of participants in this study got their information from their physician. Those present tremendous opportunities for reaching Afro-Caribbean men at the primary care level. Their expressed willingness to get annual physicals and get tested for prostate cancer can be used to get physicians to initiate the discussion about the disease and its consequences. Currently, The American Cancer Society recommends testing for all men of African

descent over 45 years but participants actually believed that testing should be started at 40 for Afro-Caribbean men. In addition to targeting Afro-Caribbean men and Afro American men I contend that it would be advantageous for all men if the primary care organizations of the U.S. Department of Health and Human Services and other physician groups initiate the discussion on prostate issues at every visit as a standard routine practice.

Implications for Policy

The major findings from this research point to a lack of awareness and low levels of education about prostate cancer, the willingness to get screened once participants are made aware, the willingness to visit their physicians on an annual basis for physicals, and the minimal effect of culture on how they think about the disease. Given that the published data on prostate cancer show the men of color are higher risk of prostate cancer and the population of Afro-Caribbean men in the United States are not located in easily identifiable communities outside of major metropolitan areas such as New York and Atlanta, Health care policy should be targeted to men of color in the United States. Such policy should continue to emphasize the importance of targeting men of color for screening and provide incentives to minimize the financial barriers because of lack of health coverage. Although the risk of dying from prostate cancer is relatively low compared to several other types of adenocarcinomas, it is particularly high for men. This study did not provide any significantly new findings that should affect how policy is specifically targeted to this population. Therefore the health policy regarding screening

recommendations and local efforts to encourage such testing should continue to be emphasized at the physician's office and through local and national efforts.

Implications for Social Change

Results from this study suggest a window into how Afro-Caribbean men think about prostate cancer and assess their risk and susceptibility to the disease. According to Pedersen, Ames, and Ream (2012), men of African descent bear the highest burden of the disease, yet little was documented about where Afro-Caribbean men get prostate cancer information. In this study, 84.6% of participants revealed that they received their information on prostate cancer from their physician, 30.8% got it online, 15.8% from reading and 7.7% from a friend.

In addition, the findings of this study add to the limited body of knowledge by partially addressing the existing gap in the literature on the health beliefs of Afro-Caribbean men towards prostate cancer. The potential social change implications can be significant with the addition of this research because a relationship was found between Afro-Caribbean men's lack of education and awareness of prostate cancer, and their willingness and likelihood of seeking early detection and treatment. Although that relationship is not new in studies of men of color, it points to the need for greater targeted emphasis within the Afro-Caribbean community, many of whom were not aware they were at significant risk. This research adds to the documented evidence that Afro-Caribbean men need to be concerned about prostate cancer, and social and political organizations that serve these communities need to take the forefront in increasing awareness. The findings regarding the effectiveness of wives in getting their partners to

get tested is an important one because they can be key drivers in increasing screening and concern about the disease. Social change can also be impacted because readers of this research can determine if the findings may be potentially applicable to other situations. That determination would be strongly influenced if the design of this study, the assumptions of the research questions, the reasons for the sampling strategy, and the description of the theoretical position and research techniques meet the readers' criteria or satisfaction (Malterud, 2001).

Finally, the methods by which education and awareness information reaches Afro-Caribbean men might have an implication for social change. The findings show that educational and other materials targeted to Afro-Caribbean men may be necessary for increased awareness. In many metropolitan and urban cities such as the Bronx and Brooklyn, ethnic groups tend to reside in close and identifiable communities. However, in many other cities such as Minneapolis, Afro-Caribbean peoples tend to be dispersed and difficult to identify and locate. Getting that information to this group will require an organized and creative way of thinking, as well as a way of identifying and reaching the target group.

Summary

The incidence of prostate cancer in African-American men has been well documented as one of the highest in the world. Several studies have suggested that for Afro-Caribbean men, men of African descent who reside in their native countries, and Black men who have immigrated to the United States and the United Kingdom, their incidence may be either similar to, or higher than that in African-American men.

However, few qualitative studies exist that look into how Afro-Caribbean men perceive their risk and susceptibility to the disease. Therefore, it has been difficult to target this group strategically for early detection efforts.

The incorporation of the synthesized model of the HBM and TRA assisted in explaining the relationship between beliefs and behaviors relative to health, culture, ethnicity, and health care from a culturally sensitive perspective and was central in addressing the research questions in this study. I utilized a qualitative, phenomenological design and outlined the data collection methods, limitations, delimitations, scope, and assumptions that were essential in helping to arrive at a thorough understanding of how those components impacted the design, findings, and conclusions.

In a review of the data on the etiology of prostate cancer there were many unanswered questions about the causes of the disease. Several researchers provided differing views on why there were glaring differences in incidence and mortality rates based on race, ethnicity, geographic location, and in some cases, culture. Apart from studies conducted on African-American men and Black men in the United Kingdom, there were very few studies available on prostate cancer and other men of African descent. One of the more glaring findings was the lack of qualitative data on Black men and their perceptions of prostate cancer.

Very high prostate cancer incidence rates have been reported for men in the Caribbean region (Glover et al., 1998; Gibson et al., 2010) and despite the effect on men's health and mortality in the Caribbean region, qualitative data on how Afro-Caribbean men perceive the disease and their susceptibility to it is minimal. Of the few

studies that are available, the percentage of participants from the Caribbean is either quite small (Pedersen et al., 2012), or the number of Caribbean countries represented is limited to two or three countries (Kleier, 2004).

In an attempt to get a better understanding of the perceptions, attitudes, and experiences of Afro-Caribbean men, I conducted a qualitative phenomenological study where I held in-depth face-to-face interviews with 13 Afro-Caribbean men who have resided in the United States for 10 years or greater. The interviews and questions formulated and were asked in order to answer the three research questions outlined in this paper. The sampling logic, sampling population, data collection process, demographic profile of participants, data analysis process, tools, findings, and the presentation of themes that addressed each research question were also addressed.

In analysis of the research, it was found that education and awareness were primary factors in whether Afro-Caribbean men were motivated to seek screening or any type of prostate cancer intervention. The majority of participants seemed eager to acquire the necessary information that would help them make decisions about diagnosis for prostate cancer and increasing their chances of a long life. Although several studies of men of African descent in the United States showed that lack of health insurance was one of the main barriers to whether or not men were screened for the disease, almost all the men in this study had access to health insurance, had an average educational level of a four-year college degree, and once they had information about the disease, they seemed eager to get screened. In addition, a significant percentage (92.3%) of men had a prostate screening of some kind even though several of them did not know what the test was for.

The findings from this study seem to suggest that participants clearly associated an early diagnosis with increasing the likelihood of survival rather than discovering they had the disease later because they were symptomatic. These findings also suggest that education efforts should also be targeted to wives as well, as they were mentioned as strong motivators in whether or not Afro-Caribbean men go to the doctor and initiate a discussion on prostate issues.

Conclusion

The findings from this study show that education and awareness are primary factors in whether Afro-Caribbean men would be motivated to seek screening or any type of prostate cancer intervention. The majority of participants seemed eager to acquire the necessary information that would help them make decisions about what to do to get an early diagnosis for prostate cancer and increase their chances of survival.

Several studies of men of African descent in the United States showed that lack of health insurance, low educational attainment, and low income were some of the main barriers to whether or not men were screened for the disease. However, almost all the men in this study had access to health insurance, had an average educational level of a four-year college degree, and once they had information about the disease, they seemed eager to get screened. In addition, a significant percentage (92.3%) of men had a prostate screening of some kind even though several of them did not know what the test was for.

It was anticipated that the cultural component would be a significant factor in Afro-Caribbean men's attitudes, beliefs, and perceptions about the disease but that was not found to be the case. That finding was noteworthy because rather than keeping their

ethnocultural traditional health beliefs as one might presume, participants seemed to have been influenced by the health beliefs of the dominant U.S. culture in which they are immersed. The required minimum residency criterion for qualification for this research was in an effort to minimize the cultural influence. It is possible that the minimum amount of time required for U.S. residency in order to participate in this study affected the findings relating to culture.

The attitudes towards the disease were influenced by the low level of awareness and all participants stated that once their awareness was increased, their attitudes would also change. Although participants' attitudes towards the DRE could be assessed to be culturally driven, several studies of African American men showed the same concern and attitudes (Clarke-Tasker & Wade, 2002).

Finally, the findings from this study seem to suggest that if prostate cancer education and awareness programs were targeted to reach this group, they would take the initiative and have their prostate tested annually. Twelve participants (92.3%) stated that they planned to get a prostate cancer test in the near future, with 4 (33%) indicating that they will do so within the next six months, and seven (58.3%) within the next year once they were aware of what the tests were for (Table 2). Participants clearly associated an early diagnosis with increasing the likelihood of survival rather than discovering they had the disease later because they were symptomatic. These findings also suggest that education efforts should also be targeted to wives as well, as they were mentioned as strong motivators in whether or not Afro-Caribbean men go to the doctor and initiate a discussion on prostate issues.

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Appendix A: Consent Form

You are invited to take part in a research study of Prostate cancer and Afro-Caribbean men. The researcher is inviting Caribbean men of African descent between the ages of 40 and 75 years old to be in the study. This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part. This study is being conducted by a researcher named Harold E. Taitt, who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to investigate the experiences, perceptions, and beliefs of Afro-Caribbean men relative to prostate cancer.

Procedures:

If you agree to be in this study, you will be asked to:

- Complete a demographic information form
- Participate in an interview lasting approximately 30 – 40 minutes with the possibility of a follow-up contact at a later date for clarification or explanation of your responses.
- Consent to an audio recording of the individual interviews

Here are some sample questions:

1. What do you know about prostate cancer?
2. What do you know about your risk of getting prostate cancer?
3. How do you think prostate cancer would likely affect your lifestyle?

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. If you decide to join the study, you can change your mind at any time during the study.

Risks of Being in the Study:

Being in this study will not pose risk to your safety or wellbeing, and your risk of harm will not exceed the probability and magnitude of harms or discomfort greater than those normally encountered in daily life.

Potential Benefits of Being in the Study:

The findings from this study may provide direction on whether prostate cancer education and outreach efforts and methods tailored to African-American men are effective in raising the awareness of prostate cancer within the Afro-Caribbean community in the United States. It may also help to increase awareness of the significant problem of prostate cancer within the Afro-Caribbean community and outline strategies for prostate cancer education and early detection testing that are targeted specifically to Afro-Caribbean men.

Privacy:

Any information you provide will be kept confidential. As the sole researcher, I will not use your personal information for any purposes outside of this research project. Also, I will not include your name or anything else that could identify you in the study reports. Data will be kept for a period of at least 5 years, as required by Walden University.

Contacts and Questions:

You may ask any questions you have now. If you have questions later, you may contact me. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. Dr. Endicott is the Walden University representative who can discuss this with you. Her phone number is 612-312-1210.

The researcher will give you a copy of this form to keep.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I understand that I am agreeing to the terms described above.

Printed Name of Participant	
Date of consent	
Participant's Signature	
Researcher's Signature	

Appendix B: Demographic Information

1. What is your age? _____
2. Were you born in the United States? Yes _____ No _____
 - a. If answer is No, Country of Birth _____
 - b. How long a resident of the United States? _____
3. Marital Status
 - a. Single _____
 - b. Married _____
 - c. Divorced _____
 - d. Widowed _____
 - e. Separated _____
4. Years of school completed. (Please circle the appropriate number)

1 2 3 4 5 6 7 8 9 10
11 12 13 14 15 16 17 18 19 20+
5. What is your general state of health? Please check one:

Excellent_____ Good_____ Average_____ Poor_____
6. When was the last time you had a physical exam? (Please check one) Never _____

Less than 1 year ago_____ 1 to 2 years ago_____

More than 2 years ago_____
7. Have you ever had a prostate test or exam? (please check one) Yes _____ No_____
8. If answer was "Yes" to Question 7, what kind of prostate test or exam? (Please check all that applies) PSA _____ Digital Rectal _____

9. If you answered “No” to question 7, do you plan to have a prostate exam in the near future? (Please check one) Yes _____ No _____
10. If you answered “Yes” to question 9, how soon do you plan to have such an exam?
Within the six months _____ within the next year _____
11. Do you know or have you known of someone who had prostate cancer?
(Please check one) Yes _____ No _____
12. If you answered “Yes” to question 11, what was (is) the nature of your relationship with that (those) person(s)? _____
13. Where have you received information about prostate cancer?
a. Work _____ on line _____ Doctor _____ Other _____
b. If other, please specify _____

Thank you for taking the time to complete this questionnaire.

Appendix C: Invitation to Participate Letter

Dear

I will be conducting interviews as part of a doctoral research study intended to increase the understanding of prostate cancer and Caribbean men of African descent who reside in the United States. The title of the proposed study is “Prostate Cancer and Afro-Caribbean Men: A Phenomenological Study of Experiences, Perceptions, and Beliefs.” As an Afro-Caribbean man who has resided in the United States for 10 or more years, you are in an ideal position to provide valuable insights into how Caribbean men of African descent see themselves in terms of their awareness and susceptibility to prostate cancer, and how they get information on testing and treatment of this disease.

Participants for this study also need to be between 40 -75 years old.

The interview will last approximately 30-45 minutes and is very informal. The interviews will be audio-recorded and you will have the option of checking the recorded data for accuracy. As the sole researcher, I am simply trying to capture your thoughts and opinions and beliefs on prostate cancer from the perspective of an Afro-Caribbean male.

There is no compensation for participating in this study and your responses will be kept confidential. However, your participation will contribute to existing research, and findings could lead to greater public understanding of prostate cancer and Afro-Caribbean men.

I will contact you within 2 weeks from the date of this letter. If you are willing to participate, we will schedule a suitable time and location for the interview at that time

Thanks!

A handwritten signature in black ink, appearing to read "H. Taitt", with a small flourish at the end.

Harold Taitt

Appendix D : List of Participant Questions

1. Please tell me what you know about prostate cancer?
 - i. Risk factors/causes; prevention; treatment
2. As an Afro-Caribbean man, what are your concerns about prostate cancer?
3. Tell me what you know or have heard about testing for prostate cancer.
4. As an Afro-Caribbean man, how likely are you to have a test for prostate cancer if you do not have symptoms?
5. Why do you think Afro-Caribbean men do not want to get tested for prostate cancer?
6. How do you think having prostate cancer would likely affect your life, lifestyle and that of your family?
7. If you were diagnosed with prostate cancer, what steps would you take after the diagnosis?
8. How long after a prostate cancer diagnosis do you think you would survive?

Appendix E: Confidentiality Agreement

Name of Signer: Cynthia Abdulla

During the course of my assistance in editing and transcribing the data for this research: "Prostate Cancer and Afro-Caribbean Men: A Phenomenological Study of Experiences, Perceptions, and Beliefs," I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems/devices I'm officially authorized to access and I will not demonstrate the operation or function of systems/devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature:

Date: