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LOMA LINDA UNIVERSITY  
School of Behavioral Health  
in conjunction with the  
Faculty of Graduate Studies

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Prostate Cancer Screening of Heterosexual Caribbean American and  
African American Men and their Partners

by

Horatius C. Gittens

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A Dissertation submitted in partial satisfaction of  
the requirements for the degree  
Doctor of Philosophy in Marital and Family Therapy

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March 2015

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

\_\_\_\_\_, Chairperson  
Colwick M. Wilson, Professor of Counseling and Family Sciences

\_\_\_\_\_  
Curtis A. Fox, Professor of Counseling and Family Sciences

\_\_\_\_\_  
Susanne Montgomery, Professor of Social Work and Social Ecology

\_\_\_\_\_  
Winetta Oloo, Assistant Professor of Counseling and Family Sciences

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## IN DEDICATION

This work is dedicated in loving memory to my late parents, Jerome Cornelius Whittington Gittens, Sylvia Gittens, and Vida Gittens. These souls are the persons who served as the cradle of my nurturing, the sources of my spiritual resolution, moral convictions, academic motivation, personal inspiration, and internal grit. Their physical presence is always missed but the values they espoused and instilled in me live on and on. My father was the only one of these three souls who was still alive when this academic adventure began. I hoped that he would have been able to witness the completion of this academic course but he did not make it to the end. I desire to honor him by demonstrating continued confidence in the God he taught me to love and honor.

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## ABBREVIATIONS

AA	African American
DRE	Digital Rectal Examination
EA	European American
PcA	Prostate Cancer
PSA	Prostate Specific Antigen
SI	Symbolic Interactionism
WIA	West Indian American

## ABSTRACT OF THE DISSERTATION

Prostate Cancer Screening of Heterosexual Caribbean American and African American Men and their Partners

by

Horatius Gittens

Doctor of Philosophy, Graduate Program in Marital and Family Therapy

Loma Linda University, March 2015

Dr. Colwick M. Wilson, Chairperson

The incidence and prevalence of prostate cancer are very alarming among men in general, among African American men more narrowly, and among Caribbean American men more specifically. While the disease has variable impact on men of different racial and ethnic backgrounds the impact of the disease on diagnosed Caribbean American men and their families is of particular importance. Prostate cancer screening decisions and behaviors can be very helpful in prevention, early intervention, treatment and recovery from prostate cancer. This research uses a symbolic interactionist framework within a family systems approach towards evaluating and understanding the experience of prostate cancer screening decision making among heterosexual Caribbean American men and their partners. A family systems approach is a comprehensive approach that considers important concepts relevant to the experience of illness and decision making surrounding health maintenance decisions. Symbolic interactions theory (SIT) focuses on the associations between symbols or shared meanings and verbal and non-verbal interactions actions and communications. It is a framework for understanding how human beings engage in relationships with each other and illustrates how they experience a variety of decision making processes. People are seen as employing their reasoning and

symbolizing capacities and flexibly interpreting circumstances while simultaneously adapting to the same circumstances based on how they interpret the situations they confront. A qualitative research using Focus Groups of with 26 men and 24 women who identified as heterosexual Caribbean American and African American men and their partners was done. Their prostate cancer screening decision making experiences were evaluated in order to aid in the development of hypotheses and generate understanding about preventive and intervention strategies for serving the African American and Caribbean American community.



## **CHAPTER ONE**

### **INTRODUCTION**

Prostate cancer is a global health problem. It is the second most frequently diagnosed form of cancer among men worldwide with 12% of all male cancer cases (Baade, Youlden & Krnjacki, 2009) second only to lung cancer (Center et al., 2012; Ferley et al., 2010). Although it is a threat to all men it has variable prevalence, incidence, and mortality rates among men in different countries, of different ages, of different racial/ethnic, and cultural backgrounds. For example, it is more prevalent in more developed countries while simultaneously accounting for much less cancer diagnoses among men in less developed countries (Baade et al, 2009; Ferley et al, 2010). The aging of the global population particularly in the more developed countries seem to guarantee increase incidence of prostate cancer due to increased age (Center et al., 2012). Age, being from the black race/ethnicity, and a familial history of the disease are the established risks for the disease (Platz & Giovannucci, 2006). Globally, men of African descent seem to experience the highest incidence of prostate cancer; consequently the need for a deliberate investigative focus on African American and West Indian men of African descent to better understand their particularly vulnerability to the disease (Gronberg, 2003).

There is a range of responses demonstrated by men who are diagnosed with prostate cancer and others who contemplate the possibility of prostate cancer diagnosis. Similarly, there are differences in the challenges diagnosed individuals confront. The variety of responses and differential challenges include variability in: preventive behaviors, attitudes towards screening behaviors, intentions about screening behaviors,

screening behaviors, manifestations of the disease, coping strategies, psychological and mental health outcomes, barriers to screening and treatment, disease, in physiological responses to treatment for the disease, and the functioning of the families of the diagnosed persons (American Cancer Society, 2013).

While persons diagnosed with prostate cancer are undoubtedly experiencing life changing and life disrupting challenges, the partners and family members of the men in marital and dyadic relationships are also affected. For example, Caribbean American men have unique cultural and ethnic backgrounds that may influence their psychological processes; their cognitions, motivations, attributions, expectations, and intentions. These psychological processes may in turn impact their behaviors in families when they are confronted with major illness diagnoses (Betancourt & Flynn, 2007).

Family structure, family functioning, and cultural influences and their relationship to attitudes towards screening behaviors, intentions about screening, and meanings attributed to screening behaviors allow for different models of assessment, methods of intervention in therapy, and planning for family coping strategies as families engage in disease preventive behaviors and/or adjustment to illness. A family systems conceptualization utilizing a symbolic interaction theoretical framework can provide at least a threefold foci of a) determining the unique meanings attributed to the prostate cancer related issues, b) the evaluation of unique meanings and interactions of family structure and family functioning, and c) clarifying the uniqueness of the experiences heterosexual West Indian American and African American men and their partners screening decisions to enable better prostate cancer screening decision making and behaviors (Addis & Mahalik, 2003).

Numerous health interventions and coping strategies are necessary in order to help alleviate the onset of prostate cancer and the negative effects of prostate cancer on diagnosed persons and on persons likely to be diagnosed. The family system of the diagnosed persons, however, will invariably influence men's responses to various life challenges and health behaviors. For example, a family's overall system may be implicated in family functioning before any illness and may be involved in health maintenance attitudes, screening intentions and screening behaviors. This suggests that it may be appropriate to investigate the potential bearing of family dynamics on the possible responses of men diagnosed with prostate cancer or at risk for this disease (Weston et al., 2007).

Though Black West Indian American men share a common African racial heritage with each other there are important ethnic and cultural differences within this population. Variability in ethnicity and culture in areas such as values, beliefs, norms, and ideals, and psychological processes may result in different attributed meanings and interactive interpretations when they need to address diverse life threatening situations and illnesses. One of the ways in which these differences are manifested may be in their experiences of prostate cancer screening decisions between them and their partners. Given the prevalence of prostate cancer among West Indian American men they may benefit from an examination of the meaning of family experiences that are related to Prostate cancer screening decision making.

## **CHAPTER TWO**

### **PURPOSE OF PRESENT STUDY**

Family Systems perspective may contribute to an understanding of family functioning after the onset of a particular illness or disease; particularly the diagnosis of prostate cancer. The meaning attributed to prostate cancer and its effect on a person and/or his family is potentially important when considering prostate cancer screening decisions. The meanings attributed to prostate cancer, prostate cancer screening, family quality and family structure may all contribute to a unique experience surrounding decisions about screening behaviors. Screening, early detection, early intervention, and lifestyle factors are important issues in prevention and treatment of the disease, hence family systems perspectives may be adequate in developing interventions that that can enhance the experience of screening decisions, lifestyle adjustments, and treatment decisions in instances of disease diagnoses. Meanings attributed to things and family interactions may be implicated in the etiology, treatment decisions, and coping strategies in dealing with the disease. These interactions may be evaluated within a Family System perspective.

The purpose of this study is to examine with the use of focus groups how West Indian Americans experience prostate cancer screening decisions among heterosexual West Indian American men and their partners. Through the use of focus groups this study will explore how they utilize an understanding of meanings, experiences, perspectives, and conceptualizations of issues through which various cultural influences affect the experience of prostate cancer screening decisions in heterosexual Caribbean American men and their partners. Within the study's approach questions are asked that seek to

understand the role of cultural issues such as (masculinity, spirituality, and fatalism) on prostate cancer screening decisions of this segment of the minority and immigrant population.

This study seeks to improve on existing literature by focusing on symbols and meanings attributed to things and family functioning within a selected minority population that is vulnerable to prostate cancer and will enhance knowledge about possible intervention techniques to aid in enhancing screening decision making and screening behaviors and lifestyle practices that impede or enhance disease onset. This study is important in that it focuses on the attempt to understanding the experience of prostate cancer screening decisions among heterosexual Caribbean American and their partners. It will in the process consider the meaning reported by participants and attempt to understand how cultural factors and their influence on beliefs, attitudes, and behaviors related to prostate cancer screening decisions.

### **Statement of the Problem**

African Americans are disproportionately at risk for prostate cancer. Crawford (2003) observed that African Americans have among the highest rates of prostate cancer in the world (275.3 per 100,000 men). It is nearly 60% higher than among Caucasians (172.9 per 100,000), which itself is higher than the rates among Hispanics, (127.6 per 100,000), and the rates among Asians/Pacific Islanders (107.2 per 100,000). Also, the mortality rate for African Americans was 2.3 times higher than that of Caucasians, 3.3 times higher than that of Hispanics, and 5 times higher than Asians/Pacific Islanders for the period from 1992 to 1999. Although the gap between the 5-year survival rates

between African Americans and Caucasians have narrowed, the survival rates for African Americans remains lower than that for Caucasians (93% versus 98%) for cases diagnosed during the period 1992 to 1998. Recent data (Crawford, 2003; Thompson et. al, 2001; Graham-Steed et al., 2013; also see Brawley, 2012) seem to consistently affirm that men of African American descent have the highest rates of prostate cancer in the world, are at greater risk for early onset of the disease and delayed presentation for treatment, and they demonstrate poorer outcomes when compared to men of Western European descent. Thompson et al. (2001) claimed that African American men have 47% higher incidence of prostate cancer than Caucasian men and a 128% higher mortality rate from the disease in the USA. The burden of prostate cancer seemed to consistently vary according to race as Black men were reported to have higher incidence of prostate cancer, presenting more advanced stages of disease at times of diagnosis, and higher mortality. Racial difference seemed to account disparity in tumor biology and treatment responsiveness while societal explanations for the disparity still included access to health care, screening patterns and treatment black men received (Graham-Steed et al., 2013; Brawley, 2012).

African American men, however, are not a monolithic group; there is important diversity within this group. For example, there are Caribbean born blacks as compared to native born blacks in the US as well as blacks born in the continent of Africa as compared also to native born blacks in the USA (Williams et. al., 2007; Williams & Wilson, 2004). The importance of the study is emphasized because West Indian American men of African descent are a unique sub-sector of the African American population at a risk for developing prostate cancer and there is information suggesting that the onset of prostate cancer can have negative effects on the men and a

corresponding adverse bearing on their spouses and/or significant others in their dyadic relationships. Intention to use prostate cancer screenings, knowledge about prostate cancer, awareness of the benefits of prostate cancer screening, and participation in prostate cancer screening contribute to early detection, early intervention, and better survival from prostate cancer. Though studies have been done that address African American men and prostate cancer there has been few studies that focus on West Indian American men and their partners and none reviewed that seem to address the experience of prostate cancer screening decisions among heterosexual West Indian American men and their partners.

### **Research Questions**

The two research questions that are addressed in this study are: 1) How do heterosexual West Indian American and African American men and their partners understand their experience of prostate cancer screening decision making? And 2) How do heterosexual West Indian American and African American men and their partners manage their experience of prostate cancer screening decision making in order to achieve better screening outcomes?

### **Importance of study**

The Black American population remains underserved in medical and mental health services and there is still a need to better understand this population to offer better medical and mental health services and family therapy. West Indian American as a subset of the African American population is a rapidly growing population within the United

States. The growth of this population will result in increased in health care services of all types within the population sector. Medical, mental health and family therapy services often are improved by having knowledge about the functioning of particular immigrant populations. Since the PcA screening decisions and behaviors seem to contribute to early detection of prostate cancer and earlier diagnoses seem to contribute to earlier and more effective treatment intervention it seems appropriate and helpful for the experiences of screening decision making among heterosexual West Indian American men and their partners to be better understood. This study, therefore, has the potential to add unique information about West Indian American families within the United States.



## **CHAPTER THREE**

### **LITERATURE REVIEW**

Prostate cancer is a worldwide health threat to the male population. The incidence of prostate cancer varies worldwide with the highest rates occurring in the Caribbean, United States, Canada, and Scandinavia while the lowest rates occur in China and other parts of Asia. The variability of the incidence and prevalence of prostate is largely due to a number of factors such as genetic susceptibility, exposure to unknown external risk, lifestyle, and differences in health care or any combination of the aforementioned factors (Gronberg, 2003). Even if there is uncertainty about all of the risks for prostate cancer some of the confirmed risks for prostate cancer are age, black race/ethnicity and a familial history of the disease (Platz & Giovannucci, 2006). In the more developed countries prostate cancer is the most frequently diagnosed cancer among men accounting for 19% or one in five of all cancer diagnoses while simultaneously accounting for one in twenty (5%) of cancer diagnoses among men in less developed countries (Baade, Youlden, & Krnjacki, 2009; Ferley et al., 2010).

Mortality rates due to prostate cancer also vary worldwide; the highest rates are documented in the Caribbean and Scandinavia while the lowest documented rates are in China, Japan, and countries of the former Soviet Union. Thus, prostate cancer remains a significant health risk within the United States of America. For example, in 1998 prostate cancer accounted for 180,000 new cases and almost 40,000 deaths in the USA (Dale, Sartor, Davis, & Bennet, 1999). In 2010 prostate cancer was the most frequently diagnosed cancer among men of all races in the United States (126.1 per 100,000) and the second leading cause of death among men in the United States (21.8 per 100,000); second to lung cancer (60.1 per 100,000) (Center for Disease Control and Prevention, 2013). The

expectation of a fourfold increase of the male population 65 years and older between the years 2000 to 2050 predicts an increase in the number of men who will be diagnosed with prostate cancer and who may need treatment for this disease (Dale et al., 1999; Crawford, 2003; Platz & Giovannucci, 2006). The International Agency for the Research on Cancer (IARC) (2010) documented that prostate was the sixth leading cause of death among men worldwide and the ninth leading cause of death among both sexes combined worldwide (International Agency for the Research on Cancer, 2010).

When the global incidence and prevalence of prostate cancer is discussed the fluctuating nature of these phenomena over the years together with the variability of its diagnoses in men in different regions and countries is also recognized (Baade et al, 2009; Ferley et al, 2010). For example, there are observations about the changes over time of the incidence and mortality of prostate cancer and the changes seem to be associated with the increased availability of health care in specific countries and regions of the world (Schroder & Robol, 2012). There was a 24-fold worldwide variability of the PcA incidence in 2008 with the highest estimated incidences in Australia/New Zealand, North America, Western Europe, and the Caribbean. The lowest estimated rates were in central Asia, northern Africa, and eastern Asia. Alongside this observation was the reality that the estimated PcA mortality also varied 10-fold worldwide with the highest estimated mortality in the Caribbean, in South America and in some countries in western and eastern Africa while the lowest mortality rates were in North America, most countries of Asia and in northern Africa (Center et al., 2012). The countries with the better resources seemed to be having increased incidence and decreasing mortality from PcA since 1993,

suggesting that earlier detection and earlier intervention may be having a positive result in these regions (Schroeder & Robol, 2012; Center et al., 2012).

### **General Incidence and Risk Factors for Prostate Cancer**

According to the American Cancer Society (2013) the risk factors associated with prostate cancer include age and ethnicity, family history and genetic susceptibility, diet, and hormonal factors. The focus of this research seems to be accentuated by the apparent association between race/ethnicity and prostate cancer among men of African descent. Crawford (2003) observed that African Americans had among the highest rates of prostate cancer in the world (275.3 per 100,000 men). The rate was nearly 60% higher than among Caucasians (172.9 per 100,000), which itself was higher than the rates among Hispanics (127.6 per 100,000), and the rates among Asians/Pacific Islanders (107.2 per 100,000). The mortality rate for African Americans was 2.3 times higher than that of Caucasians, 3.3 times higher than that of Hispanics, and 5 times higher than Asians/Pacific Islanders for the period from 1992 to 1999.

There has been a narrowing of the gap of the 5-year survival rates between African Americans and Caucasians but the survival rate for African Americans remains lower than that for Caucasians (93% versus 98%) for cases diagnosed during the period 1992 to 1998. In addition to consistently indicating that men of African descent have the highest rates of prostate cancer in the world, the current data show that African American men are also: a) at greater risk for early onset of the disease, b) display delayed presentation for treatment, and c) demonstrate poorer outcomes when compared to men of Western European descent (Crawford, 2003; Thompson et al., 2001). Thompson et al.

(2001) claimed that in the United States African American men have 47% higher incidence of prostate cancer than Caucasian men and a 128% higher mortality rate from the disease. Important also is the fact that according to the American Cancer Society (2013) the risk factors associated with prostate cancer include age and ethnicity, family history and genetic susceptibility, diet, and hormonal factors.

Thus far some of the details which have been noted include: the global incidence and prevalence of prostate cancer among men of all races, the variability of its incidence in developed versus underdeveloped countries, the variability of its incidence among men of different races/ethnicities with special notice of its higher incidence among men of African descent with the highest documented incidence among African American and West Indian men, the risk factors associated with prostate cancer and the observation that race/ethnicity is among the well-established risk factors, the observation that the death rates resulting from prostate cancer is highest among African American and West Indian/West Indian American men, and the salient finding that African American and West Indian American men with later stage prostate cancer. These details seem to make a plausible case that research needs to be done to better understand the experience of prostate cancer screening decisions among heterosexual West Indian American men and their partners. The uniqueness of the experience is probably linked a peculiar meaning that this important sector of the population has developed over time. That is the focus of this research.

## **West Indian American – Their Migration to the USA, Race and Ethnicity/Culture**

West Indian immigration and the United States has been an important topic of discussion over a number of years. Waters, (1999) observed that the changing demographics of many urban areas have been the direct consequence of this phenomenon. In general, factors that contribute to migration of peoples are categorized into two groups; push and pull factors. Push and pull factors are economic, political, cultural, and environmentally based. A push factor is a forceful dynamic, which relates to the country or place from which a person migrates or a place a person desires to leave. A pull factor is something concerning the country to which a person migrates or to which a person desires to migrate. It is generally a benefit/a spectrum of benefits that attract people to a certain place. Push and pull factors are usually considered as north and south poles on a magnet. Descriptively, these factors also include a security dimension and an economic dimension. A security dimension of migration may be comprised of natural disasters, conflicts, threats to individual safety, and poor political prospects. The economic dimension of migration may refer to poor economic situation and poor situation of national markets (Ueda, 1994; Chuang & Gielen, 2009).

There are racial/ethnic, and cultural issues, which also influence this study because these realities may be associated with the etiology, discovery, screening, general health behaviors, treatment, and recovery from prostate cancer among individuals in the targeted population. Current conceptualization of race allows it to be viewed as a multidimensional construct and sometimes important distinctions are missed as one considers racial categories (Carter, 1993; Parham & Helms, 1981). There has been

misunderstanding about the diversity, which exists between racial groups, as there is ignoring the fact that there is greater diversity within racial groups than between racial groups (Carter, 1993; Parham & Helms, 1981). There may be biological realities relevant to this racial/ethnic group that may have implications for prostate cancer diagnosis, development, and treatment.

Caution is always needed when considering Blacks within the United States because of the within-group variability of US Blacks. The diversity within the African American population is related to the fact that that the population includes immigrants from multiple regions including Brazil, the United Kingdom, the Caribbean, Central America, and from the continent of Africa. Of importance also is that 6 percent of the black population in the USA are foreign born and another 4 percent are born to foreign parents and most of them reside in specific geographical regions of the country mainly New York City, Washington D.C, and South Florida (Schmidley & Gibson, 1999; Wilson & Williams, 2004). The within-group variability of the Black population is further related to the fact that Caribbean Blacks, for example, have different colonial heritage, Spanish, French, Dutch, and English (Wilson & Williams, 2004). Similar variability can be noted in Blacks from the continent of Africa.

### **Blacks from the Continent of Africa**

Ethnicity is understood as an affiliated group who interacts with each other and thereby become the means by which culture is transmitted (Betancourt & Lopez). An ethnic group may have dissimilar phenotypic racial presentations but common cultural backgrounds and engage in the cultivation and transmission of a common culture. In this

work individuals from a common geographical location (particular West Indian or Caribbean Islands) may be understood as having similar ethnicity. However, the relocation of these men of different ethnicities into a new territory may result in the inculcation of newer cultural norms, beliefs, and values. According to Berry (1985) the interaction of different ethnic groups results in newer cultural influences.

As people are relocated into new territories due to factors such as voluntariness, mobility, or permanence (Berry, 1997), they generally become acculturated. This acculturation is a unique reality “which results when groups of individuals having different cultures come into continuous first hand contact with subsequent changes in the original culture patterns of either or both groups” (Redfield et al., 1936). Though acculturation results in changes of both cultures involved in the process of acculturation it often results in more changes in one group, the acculturating group (Berry, 1990). Therefore, one may assume that West Indian immigrants in the USA will experience cultural changes with increasing stay in the USA. Berry (1997) posits that the acculturation is both a collective phenomenon operating at the group level and a psychological phenomenon operating at the individual level.

Within a migrant population, psychological acculturation results in outcomes, which are highly variable (Berry & Kim; 1988; Murphy & Mahalingam, 2006). The psychological acculturation often results in psychological changes that are classified as: a) “behavioral shifts” (Berry, 1980), in which an individual learns new adaptive behavioral patterns; b) “culture learning” (Brislin et al., 1983), in which an individual recognizes and practices, appropriate and culturally safe practices and sheds old cultural patterns that are deemed to be inappropriate; and c) “social skills acquisition” in which

culturally adaptive social actions are cultivated. Murphy and Mahalingam (2006) demonstrate that there are varying levels of anxiety, depression, perceived stress levels, and life satisfaction for West Indian immigrants, which could be interpreted as their level of adaptation to their new culture. The relevance of acculturation in this discussion about West Indian men and prostate cancer is rooted in fact of the possibility that the acculturation adjusts, generates, or is of no effect on behaviors which are helpful or harmful in prostate cancer screening, the onset of prostate cancer, and/or the detection and treatment of prostate cancer.

### **Addressing the Wider Culture and Racial/Ethnic Issues**

Because culture has a considerable role in human behavior it may also contribute to the incidence and prevalence of prostate cancer among men. From a symbolic interaction perspective, “culture is the consensus developed by people over a long history. It is their shared view of reality, the basis ideas, values, and rules they have come to believe in” (Charon , 2009, p. 19). From a symbolic interactionist perspective the shared meaning is important even as culture, is conceptualized as a system of meaning shared by an recognizable cluster of people or sector of the population with unique ways of life transmitted from one generation to another (Betancourt & Lopez, 1993) Culture may be understood as something people are born into with ideas that they are socialized to accept as truths. People’s morals, rules, values, customs and laws are the things people accept as important principles by which they live; it is their multigenerational transferring of meaning (Charon, 2009; Rohner, 1980).



Culture must here be understood as the “human-made aspect of the environment” both objective and subjective dimensions (Herkovits, 1948). Triandis et al. (1980) elaborated on the human made aspect of the environment in the definition of culture by noting that the objective dimension of culture includes such physical inventions and constructs such as roads, bridges, buildings and tools. Subjective culture, on the other hand, includes such non-material realities as social norms, roles, beliefs, and values of a group of people. The subjective aspects of culture represent psychologically relevant details that include “a wide range of topics, such as familial roles, communication patterns, affective styles, and values regarding personal control, individualism, collectivism, spirituality, and religiosity” (Betancourt & Lopez, 1993, p. 630). Some of these aspects of subjective culture may be associated with the variables that contribute to the incidence and prevalence of prostate cancer within particular segments of the male population and may have influence on behaviors that may cause or exacerbate the onset of the disease or affect the behavioral responses to the disease within a family system. For example, the West Indian male’s unwillingness to engage in prostate cancer screening behaviors or their inattentiveness to attend to health promoting behaviors may exacerbate the incidence of later stage diagnosis of prostate cancer or the onset of prostate cancer. These behaviors may be also linked to particular cultural norms.

Betancourt and Flynn (2009) argued that there are certain population categories; race, ethnicity, country of origin, socio-economic status, gender, and religion which are the sources of culture (values, beliefs, and norms etc.). In their analysis, the population categories represent any group classification that may be a source of cultural factors. The cultural factors are aspects of culture that are socially shared among individuals in a

group and are passed on from one generation to the next. For example, beliefs about sources of good health or norms about helpful health maintenance or disease prevention practices may be beliefs and norms shared by a particular group, a nation, or a society and are socially transmitted from one generation to another. The cultural factors then are categories of meaning that directly impact the psychological processes, which are people's own cognitions, emotions, motivations, attributions, expectations, and intentions. These psychological processes then influence health behaviors such as eating habits, recreational practices, cancer screening behaviors, and decisions about prostate cancer screening behaviors.

For the West Indian American male population, behaviors that can influence health outcomes may include the very behaviors that influence health outcomes in other populations, they include: sexual activity, smoking, alcohol consumption, dietary practices, and physical activity (Weston et al., 2007). As one considers the West Indian American male population it may be necessary to determine if among these men, from a social constructionist or symbolic interactionist perspective, there is any view of masculinity that is conceptualized in a manner that is consistent with the social group's acculturation and/or their cultural understanding of male gender. That together with other beliefs, norms, and attributed meanings about health will invariably contribute to their health behaviors and family functioning (Betancourt & Flynn, 2009; Addis & Cohane, 2005; Courtenay, 2003).

## *Racial/Ethnic and Culture Issues Directly Pertaining to Prostate*

### *Cancer*

Focusing on race while addressing prostate cancer within the Black race may be a pragmatic thing (Moul, 2000). Moul contended that race may be an indicator of the cultural penchants, misunderstandings and predispositions, economic status, genetic susceptibility for cancer causing or protective behavior and cancer development within a particular racial group. Race, he thought, may practically enhance the understanding of the contributing factors of prostate cancer to particular high risk group (Moul, 2000). Often, however, a group of people possess a shared identity that fosters an increased task and morale boosting behavior. In such instance the impact of racial identity is most evident when race is perceived as salient to their current situation (Weston et al., 2007). In these instances, the power of ethnic identity can be exploited to address and deal with community challenges. Since this research is investigating the experience of prostate cancer screening decision making among heterosexual West Indian American and their partners, the benefits of considering race/ethnicity may be appropriately harnessed to address and possibly surmount some of the barriers to dealing as successfully as possible with prostate cancer.

Chinegwundoh et al. (2006), while investigating the ethnic differences in the incidence and presenting features of men diagnosed with prostate cancer, compared European Caucasian, South Asian, and African-Caribbean men in North-East London. The results of their investigation revealed that Afro-Caribbean men had a three times greater risk of developing prostate cancer than European men, while simultaneously noticing that South Asian men had a lower risk than European men for developing

prostate cancer. This study sampled men 50-years-old and above and investigated in increments of 5 years. It was noted, further, that for every age group the age specific incidence rates were higher among Afro-Caribbean than among European men (Chinegwundoh et al., 2006).

Ethnic differences in the presentation of prostate cancer appeared more complicated by the finding that African American had a more aggressive disease as compared to European American (EA) men (Thompson et al., 2001), and the discovery that race remains an independent predictor of survival outcome, after controlling for confounders in men with advanced prostate cancer and in younger men (Powell et al., 2004). These realities elevate the importance of assessing how the family functions as an interconnected network of individuals with mutual influence on each other and are also influenced by their wider cultural community; their systemic family functioning. This type of assessment is necessary to foster help to families before and after disease presentation and this assessment very likely elevate the need the need for exploring strategies rooted in systemic family functioning to do both preventive and therapeutic interventions for West Indian American and African American families. Similarly, by understanding how the family functions in the context of its larger social and cultural contexts and influences, comparable approaches are necessary to promote aggressive screening among this ethnic group.

While the incidence of prostate cancer and the nature of the tumor at time of cancer detection (Thompson et al., 2001) show racial variability, Peters and Armstrong (2005) suggested that race does not independently predict treatment outcomes. These authors asserted that for Blacks and Caucasians “equal patients who receive equal

treatment have equal outcomes” p.116. The challenge is for health systems to develop strategies to offer and ensure equality of treatment between races. Achieving equality of treatment remains an elusive goal since the outcomes manifested when the races are compared remains disparate (Thompson et al., 2001).

The facts remain that African American men have earlier onset of prostate cancer, higher prostate-specific antigen levels, more advanced stage of cancer at the time of diagnosis, and higher mortality than Caucasian men (Thompson et al., 2001). Of men with metastatic prostate cancer, African-American men remain more likely than Caucasian men to be diagnosed with the disease, present with the disease at a more advanced stage, have a poorer performance status when afflicted with prostate cancer, develop the disease at an earlier age, manifest higher PSA levels have a lower quality of life in the disease state, and are more likely to die of the disease than their Caucasian counterparts (Thompson et al., 2001). Thus, Thompson et al. (2001) concluded that “African-American men with metastatic prostate cancer have a statistically significantly worse prognosis than White men that cannot be explained by the prognostic variables explored in the study” (p. 219). Based on these facts the aspirations of West Indian American and African American men at this time should include practical strategies to achieve early detection, appropriate health behaviors for all men and effective treatment for West Indian America and African-American men diagnosed with prostate cancer.

### *Attention to the Wider Group of Men of African Descent – West*

#### *Indians*

The phenomenon of racial/ethnic differences in the prevalence of prostate cancer

in African-American men when investigated further by considering non-White racial and ethnic groups within and outside the United States continue to indicate troubling racial variability issues. Mallick, Blanchet, and Multigner (2005) reported that Guadeloupe, a French Caribbean territory with 420,000 inhabitants, 90% of whom are of African descent, has one of the highest incidences of prostate cancer in the world. In Guadeloupe over the period 1995 to 2003 study showed a relatively stable number of cases from 1995 to 1999 (92.5 to 88.8 per 100,000) then a rapid increase from 2000 to 2003 (100.9 to 168.5 per 100,000). Information from Martinique, another French Caribbean territory with similar population composition shows a prostate cancer prevalence that is similar (96.3 per 100,000). In Mainland France the incidence of prostate cancer was 54.4 and 75.3 for 1995 and 2000 respectively (Mallick et al., 2005). The disparity seemed important because the health care quality on these two Islands is of high standard while the dissimilarity between the populations is that on the islands the population is predominantly people of African descent while in France the percentage of men of African descent is significantly less.

In Jamaica prostate cancer has been the most commonly diagnosed cancer in men for the last 20 years. A 1998 study demonstrated that Jamaica had 304 per 100,000 cases of prostate cancer for the period 1989 to 1994 (Shirley, Escoffery, Sargeant, & Tulloch, 2002). These rates compare with the incidence of 225 per 100,000 for the Black men in the USA (Shirley et al. 2002). It was also determined that Black men of African-Caribbean heritage born in the USA had similar risk factors as Jamaican born and Haitian Born men (Chen et al., 2004). This study seemed to suggest that the risk factors for prostate cancer as demonstrated in biological markers were similar across these

subgroups (African American and West Indian American) in Brooklyn. In an attempt to estimate the incidence of prostate cancer among African-American men and Caribbean immigrants to the USA it was determined that the incidence rates of the two groups was similar (Shelton et al., 2005).

Previously, it was assumed that the rates of prostate cancer found on the continent of Africa were much lower than the observed rates in the USA, England, and the Caribbean. While there is limited information from the continent of Africa the information from the Island of Mauritius indicate an increase of PcA mortality rates at the rate of 2.2% annually from the year 2000 to 2009 (Center et al., 2012). Osegbe (1997) indicated that the incidences of PcA in some countries on the continent of Africa were similar to the USA. For example, 127 per 100,000 in Nigeria was reported (Osegbe, 1997) suggesting that the former lower rates reported in other parts of the African continent were due to underreporting of the disease (Chen et al., 2004).

Chu et al. (2011) investigated the rates of prostate cancer in the sub-Saharan African population with the purpose of doing comparison with rates in African American men. They reported a significant range in the number of cases reported from among the twelve countries from which they were able to obtain data. Substantial variability of incidence of PcA was seen across the region with the highest rates in the east, intermediate in the south and lowest in the west. Their conclusion was that by comparison the rates among African American men was considerably higher than among Black Africans. They did concede that the disparity could have been related to poorer access to health care, difficulties with reporting, difficulty with medical care access,

reporting problems, poorer estimates of at risk population, and under-diagnosis of prostate cancer (Chu et al., 2011).

These findings suggest that the African American population and Afro-Caribbean men have prostate cancer rates that may be similar even as we may remain ambivalent about prostate cancer incidences on the continent of Africa. This phenomenon of the variability of PcA rates require more research in order to better understand the reason for the higher rates of prostate cancer among men of African descent. Research is also needed in order to discover methods to promote education, enhance screening, facilitate early detection, determine more effective treatment for the disease, and to foster more effective coping strategies for diagnosed men and their partners.

Having noted the similarity of the prevalence of prostate cancer in men of African descent in various regions of the world it became important to focus on men living in the USA from a specific region. In this instance the focus on men of African descent from the West Indies. Shelton et al. (2005) investigated the incidence rate of prostate cancer among African-American men and men of Caribbean immigrant origins by comparing the rates between these groups as compared to the majority population. In this study the results from a larger population-based trial did not demonstrate any difference in the prostate cancer incidence rate between African-American men and West Indian American men age 50-years-old and older. The prostate cancer rate among men 40 to 49 years of age was similar to that reported among Caribbean men in other studies. However, this study indicated that age and family history were risk factors for prostate cancer in the cohort being studied (Shelton et al., 2005).



In context of discussions about prostate cancer and the suspicion that there are possibly biological peculiarities that place men of African descent at higher risk for prostate cancer a detailed investigation to evaluate the clinicopathological features of prostate cancer in Jamaican men was conducted on the Island of Jamaica to determine the features which are dominant in a cohort and to determine which features have prognostic significance (Chen et al., 2004; Shirley, Escoffery, Sargeant, & Tulloch, 2002). The findings from this study indicated that for the Jamaican men sampled: a) the mean age of diagnosis for prostate cancer in the cohort was similar to that noticed in African-American men, Asian, and Caucasian men in the USA. (72.3 years); b) most of the patients had symptoms of their disease at the time of their presentation as contrasted to findings in other cohort in which the men were screened for the disease - an issue that may explain the lower rates of radical prostatectomy in this study; c) higher average serum PSA levels in contrast to findings from studies in the USA were noticed suggesting a later stage of cancer at the time of diagnosis; and d) tumors were of a higher histological grade than that discovered in other studies. The established markers predictive of death were PSA levels and tumor stage. These findings suggested that the clinical presentation of prostate cancer is much later in this group than in other groups and it is in contrast to any evidence of biological differences between racial/ethnic groupings of patients with prostate cancer (Shirley, Escoffery, Sargeant, & Tulloch, 2002).

The clinicopathological features of prostate cancer in the men of USA and Afro-Caribbean populations suggest that the prognostic markers of significant value are: 1) serum PSA, 2) clinical/pathological stage, and 3) histologic grade of the tumor.

Information on other important details such as the volume of cancer in biopsies, histological subtype, perineural invasion, DNA ploidy, and other molecular markers are still very sketchy (Shirley et al., 2002).

The racial disparity in the incidence of prostate cancer appears to be important health phenomenon that still needs further investigation. However, it still seems appropriate for efforts to be made to examine the men of African descent to better understand the unique psychological factors that may be exploited to promote specific health behaviors that may improve early detection and earlier treatment intervention. It seems that it will also be helpful to enhance appropriate lifestyle improvements and changes that may help reduce the incidence of the disease and better deal with its effects on families.

### **Risk Factors for Prostate Cancer**

While the reasons for the higher mortality from prostate cancer among African American men are still unknown such risk factors as age, race, socioeconomic status, access to health care, diet, other lifestyle factors, culture, and genetics have been assessed and the belief is that each is associated with differing levels of risk for prostate cancer (Weston et al., 2007). Other factors such as family history and genetic susceptibility, environmental factors, and health behaviors are also implicated. These factors are all worthy of additional consideration.

#### **Age**

Age is a significant risk factor for prostate cancer. Over 70% of all cases of

prostate cancer are diagnosed in men over 65-years-old as contrasted to the relative rarity of the disease diagnosed in men under 50-years-of age. The probability of developing prostate cancer increases from .005% among men under 39-years-old to 2.2% (1 in 45) for those aged 40 to 59-years-old and 13.7% (1 in 7) for those aged 60 to 79 years. The lifetime risk of developing prostate cancer is 16.7% (1 in 6). Post mortem studies by histologic evidence confirm prostate cancer at even higher rates than these reports suggest (Weston et al., 2007).

### **Family History and Genetic Susceptibility**

Family history and genetic susceptibility represent a significant risk factor for prostate cancer. The risk for developing prostate cancer doubles for men who have a father or brother diagnosed with prostate cancer and the risk increases when multiple first-degree relatives have been diagnosed. Men with positive family history for prostate cancer are also diagnosed on average at 6 to 7 years earlier with PcA than men without a positive family history. It seemed that 5 to 10% of all prostate cancer cases and 40% of all cases in men under 55-years of age have a hereditary origin (Weston et al., 2007). Crawford (2003) suggested that men with diabetes mellitus appear to have a lower risk of developing prostate cancer.

### **Diet and Environmental Factors**

Diet and environment have also seemed to have some association with the development of prostate cancer. The Western lifestyle is particularly implicated; mainly the higher intake of fats, meat, and dairy products. Whittmore et al. (1996) indicated that

total fat intake was connected with prostate cancer development and diagnoses across three racial groups; Caucasians, African Americans and Asians. It was specifically asserted that about 10% to 15% of the difference in prostate cancer incidence was attributed to differences in saturated fat intake (Whittmore et al., 1996). A linkage between red meat diets and prostate cancer seemed to have also been established. Beef and dairy products are sources of dietary fatty acids, which were in turn associated with the production of the enzyme alpha-Methyl-coenzyme-M-reductase that is a source of carcinogenic oxidative damage to the prostate genome (Giovannucci et al., 1993; Veierod et al., 1997; & Gronberg, 2003). The lower incidence of prostate cancer in Japan versus the United States, it is argued, may be due to the higher intake of soybean products in Japan. Shirai et al. (2002) suggested that in Japan the soybean products are rich in isoflavones such as genestin and daidzin. Experimental studies suggested that these isoflavones may enhance a mechanism in cells to limit the development and metastasis of prostate tumors (Shirai et al., 2002).

There are some dietary factors that may also be protective against prostate cancer. Foods such as tomato, grains, fish, and meat have demonstrated some protective properties. The intake of tomatoes and tomato products –probably the lycopene a compound in the raw and processed tomato products demonstrate some protective properties and the food byproduct selenium an essential trace element found largely in grains, fish, and meat seemed to protect against prostate cancer. Foods with lycopene and selenium are also noted to be good sources of dietary protection against prostate cancer (Richmond & Chan, 2012).

There seemed to be some environmental risks associated with prostate cancer. For example, in a North Carolina study (Spangler & Reid, 2010) ground-water and environmental airborne manganese seemed to have been correlated with county level cancer mortality. Manganese in the ground water seemed to be positively associated with total cancer, colon cancer, and lung cancer death rates. On the other hand, airborne manganese seemed to be inversely associated with total cancer rates, breast cancer and lung cancer death rates while airborne and ground water manganese did not seem to be significantly related to all-cause mortality and prostate cancer (Spangler and Reid, 2010).

### **Hormonal Risk**

Hsing (2001) suggested that androgens are also associated in prostate cancer development. The growth and development of the prostate is under the control of androgen. Males castrated before puberty and those with congenital abnormalities in androgen metabolism do not typically develop prostate cancer. Prostate cancer treatment includes procedures to inhibit the production of androgen, but the plasma testosterone levels or dihydrotestosterone concentration when determined either prospectively or at time of cancer diagnosis have not been associated with increased risk of prostate cancer (Hsing, 2001).

Epidemiological studies suggest that high body mass index (BMI) may be associated with prostate cancer. Zhan et al. (2002) investigated over 400,000 men in a prospective study of men who were free of cancer at the beginning of the study. The risk of prostate cancer mortality was increased significantly for men with a higher baseline BMI. For example, men with a BMI of 35.0 to 39.9 had a 34% greater risk of dying of

prostate cancer than those with normal BMI. It was similarly demonstrated that high bone mass may increase risk of prostate cancer by about 60% to 90%. This study seemed to indicate that prostate cancer incidence rate for men in the lowest quartile of bone mass was 3.8 per 1000 person-years while it was 7.4 and 6.5 per 1000 person-years in the upper third and highest quartile respectively (Zhang et al., 2002).

### **Other Lifestyle Factors**

Other factors such as vasectomy, sexual activity, smoking, alcohol consumption, physical activity and social class have been related to prostate cancer risk (Moul, 2000). However, there should be caution surrounding these associations and conclusions because the etiology of and the differences in the clinical manifestations of prostate cancer still remain unknown even as the hormonal, nutritional, and genetic factors are currently strongly connected to the disease manifestation.

### **Importance of Screening Behaviors for PcA Diagnosis, Intervention, and Treatment - Prostate Specific Antigen (PSA) and Digital Rectal Examination (DRE)**

There seems to be a significant need for prolific screening for PcA within this West Indian American/African American community because of the problems prostate cancer pose within the community. If the men in this group are persuaded about the benefits of screening in effectively dealing with the PcA problem then an important first step may be accomplished in addressing PcA challenges. The benefits of screening are ultimately linked to their survival because early detection, timely intervention, and

treatment contribute to recovery from the disease (McDowell et al., 2013). Additionally, the benefits of screening for PcA in the community of men of African descent appear to be a much more important issue in the light of the findings about prostate-specific antigen (PSA) levels in Black men (Vjayakumar et al., 1998).

African American men with newly diagnosed prostate cancer referred for radiotherapy had higher PSA levels than their Caucasian counterparts (Vjayakumar et al., 1998). It was also discovered that even in equal access health care groups Black men had higher overall tumor volumes and higher within stage tumor volumes than their Caucasian counterparts. There are both PSA levels and tumor volumes disparities between these groups. In addition to these findings Moul (2000) reported that even without prostate cancer African-American men have higher PSA levels and higher PSA densities than their Caucasian and Hispanic counterparts. Though some (e.g., Vijayakumar et al., 1998) have suggested that this disparity in PSA levels, PSA density, and tumor volumes have been attributed to socioeconomic levels, others (Zhang et al., 2000) have asserted that the disparity is of a biological basis. Moul (2000) postulated that the issues to be resolved on this disparity include: a) greater amounts of high-grade prostatic intraepithelial neoplasia (PIN), b) higher PSA production or greater PSA “leakage,” and c) androgen stimulation associated with higher PSA production in Blacks.

Notwithstanding the disparity issues pertaining to PSA in men of African descent versus Caucasian men, PSA screening remains an important source of prostate cancer detection in Black men and an important clue for early treatment of the disease. The uses of PSA levels and digital rectal examinations (DREs) have proven to be very effective in determining the presence of prostate cancer in men of African descent. Studies (Smith et

al., 1996; Smith et al., 1997) have confirmed that Black men have more elevated PSA level than Caucasian men and PSA have allowed for a higher prostate cancer detection rate versus their Caucasian counterparts.

Another essential observation (Moul, 2000) is that “PSA screening cut-off point of 4.0 ng/ml is probably too high for younger men such as African-American men between 40 and 49 years-of-age” (p. 253). There is a proper use of PSA levels as it is employed in the detection of prostate cancer in men of African descent. Lower levels of PSA may indicate the presence of prostate cancer in Black men in contrast to Caucasian men. Because PSA levels in Caucasians are typically lower than in Black men, both Black patients and health care providers need to be aware of this racial disparity and act proactively to address their respective physiological condition. African American men are at higher risk for being diagnosed with prostate cancer if they and their health care providers are not proactive with this awareness about the disparity in the PSA levels in the etiology of the disease in the two groups un-necessary health problems may be incurred. This finding emphasizes both a need for screening to help in early detection and the awareness that lower PSA level may be indicating the presence of PcA in WestIndian/ African American men in contrast to their Caucasian peers.

### **Barriers to Prostate Cancer Screening within the Caribbean**

#### **American and African American community**

There are barriers to participation in screening, experiencing benefits from early detection, and prompt treatments for prostate cancer in communities of African American men. The observed barriers include: a) literacy level, b) distrust towards the health care



system and treatment programs, c) the race perspective, d) the myth of homogeneity within races, e) access to health care, f) non-acceptance of health related messages due to racial identity issues, g) socioeconomic status, h) knowledge about prostate cancer, and i) attitudes towards prostate cancer screening (Pendleton et al., 2008; Blocker et al., 2006; & Wray et al., 2009). Negative consequences of these barriers would likely include: lower participation in screening behaviors, inattention to health behaviors, and higher rates of mortality among racial minorities and men of lower socioeconomic status primarily because of advance stage of cancer presentation (Dale, Sartor, Davis, & Bennet, 1999). Understanding the barriers towards early detection of prostate cancer among minority groups and effectively addressing them may be effective steps in helping to diminish this variability in outcomes as compared to the majority population and men of higher socioeconomic status.

Men of lower socioeconomic status have been determined to have particular difficulties negotiating the barriers to early detection. Dale et al. (1999) observed that most men of lower socioeconomic status viewed physical examinations (DREs) negatively. In other settings the DREs were perceived as an assault on West Indian American and African American men's manhood. They also had a negative view of health care providers with a view of their inattentiveness to the issues of the African American community (Ochoa & Green, 2013; Pendleton et al., 2008; & Wray et al., 2009). They also experienced barriers such as time, monetary costs, negative impressions of the prostate examination, and lack of belief in early detection. Of lower SES men the minority who had the prostate examination did it as a part of a physical/medical examination for another chronic health condition or as part of an employer requirement

for routine job applications screening. The digital rectal examination was viewed very negatively because of concerns for physical pain, social embarrassment, and uncertainty about the value of the procedure. The majority of the sample group expressed fear and subscribed to the notion of fatalism about prostate cancer (Dale et. al. 1999). Fear seemed to be detected in other research as a barrier to African American men's participation in PcA screening (Woods et al, 2006).

The source of health information for lower SES men was typically the media with television being named the most common source. There was no significant difference between African American and Caucasian poor men with regards to their response to the barriers to early detection of prostate cancer. It is known that with early stage prostate cancer, potentially curative procedures are an option for patients but for the late-stage detection patients' curative options are not available. Therefore, overcoming barriers to early detection is essential for dealing with the morbidity and mortality of affected patients (Dale et. al. 1999).

Knowledge and attitudes about the disease appeared to be an important variable to be considered as the disease manifestation in the community is investigated and analyzed. Specifically, there appears to be no differences in the knowledge level and attitude towards screening between Black men and their Caucasian counterparts in the middle socio economic level. However, there was a significant difference between Black and Caucasian men of the lower economic status (Moul, 2000). Men of African descent had more misconceptions and believed more myths about the etiology of and mortality from the disease. Black men at this level were more unaware of digital rectal examination and blood tests that aided in the detection of the disease. They had a proclivity to be

distrustful of health care providers and believed that they would be used for experimentation (Pedersen, Ames, & Ream, 2012). While poor PcA knowledge seemed to be evident across all groups of men it was more manifested among African American men. They were more afraid of hearing bad news, had misconceptions about surgery causing cancer to spread, and believed DREs had homosexual implications and less understanding of their risk for PcA (Pedersen et al, 2012). Fears and taboos about the health care system seemed to have affected their willingness to even discuss PcA issues with their health care providers (Pedersen et al., 2014; Wray et al, 2009).

Literacy also seemed to be a problem in the lower SES Black men group in that information presented was at a level that rendered educational material about prostate cancer unintelligible for the group of men (Dale, Sartor, Davis, & Bennet, 1999; Robinson, Ashley, & Haynes, 1996; Abbott, Taylor, & Barber, 1998). The question about the effect of literacy upon knowledge about prostate cancer suggests that there is real need to understand the meaning attributed to the disease derived from interactions with cultural communities.

***Masculinity Issues and its Effects on Prostate Cancer Screening in  
the West Indian Male***

Masculinity is generally construed as a “culturally based ideology scripting gender relations, attitudes and beliefs” (Thompson & Pleck, 1995, p. 130.). Masculinity is invariably featured in the responses of men to health related issues such as screening behaviors, help seeking, treatment adherence, and other health related issues. For example, within Western society men are reinforced for thinking and behaving in accord

with traditional masculine norms such as emotional control, physical and emotional toughness, and self-reliance (Lease et al., 2010). On the other hand, behaviors associated with feminism such as emotionality, help seeking, emotional support and connection, compromise and empathetic understanding are often diminished or discouraged in men even in instances where these behaviors may be functionally adaptive and useful (Johnson et al., 2005; Mirgain & Cordova, 2007).

From a social constructionist perspective masculinity may be more conceptualized in a manner that is consistent with an individual's social group's or cultural perspectives of gender (Lease et al., 2010). Lee and Owens (2002) contended that male psychology is mutable and of a socially constructed nature and consequently one must be "oriented towards social explanations and social solutions to the problems of individual lives" (Lee & Owens, 2002, p. 213). Following this trend of thought it is plausible and probably essential for this study to embrace an understanding of masculinity and its effect on a uniquely male problem; prostate cancer screening behaviors and the rationale for exploiting the construct of masculinity in addressing the underlying challenges related to PcA screening behaviors.

Lee and Owens (2002) noted that in context of masculinity and gender research it has been understood that compared to women, men utilize health care services less, engage in less screening behaviors, and are less likely than women to practice preventive care and protective health behaviors. Men are also less willing to engage in helpful dietary practices such as reducing dietary fat intake, moderation of alcohol intake, and maintenance of healthy body weight. Coupled with these behavioral differences is the fact that men engage in more high risk behaviors in play activities that include: dangerous

driving, risky sports, alcohol and illicit drug abuse, unhelpful heterosexual sexual activities such as serial sexual relations with as many women as possible, aggressive and coercive sexual activities with women, and demonstrate hostilities against homosexual behaviors. Men are also known to dominate in criminal activities particularly violent crime when compared to women (Lee & Owens, 2002).

Masculinity is also related to lack of health care seeking as is indicated through social constructionist theory (Addis & Cohane, 2005; Courtenay, 2003; Connell 1995, 2001) in which it is argued that men's risky health behaviors such as excessive drinking, excessive smoking, and refusal to see the medical doctor are considered to be manifestations of masculine identities. Further, though help seeking behaviors are impacted by practical constraints such as time and money the behaviors are also influenced by psychological processes and masculine norms, which are a consequence of men's acculturation (Addis & Mahalik, 2003). For example, refusal to visit the doctor and bragging about such behaviors may be both a claim of being in the center of the masculine arena, demonstrating belongingness to the "stronger sex" as well as indicating male's refusal to submit to any "higher authority." Boman and Walker (2010) assessed the high conformity to masculinity norms and its association to men's perception of barriers to help seeking and suggested that Australian men who were high in conformity to masculinity were likely to perceive more barriers to help seeking. They assessed for masculinity's association with five barriers which they named: 1) "Need for Control and Self-reliance," 2) "Minimizing Problems and Resignation," 3) "Concrete Barriers and Distrust of Caregivers", 4) "Privacy," and 5) "Emotional Control", and observed that

masculinity is significantly related to all five barriers to help seeking (Boman & Walker, 2010).

Prostate cancer screening behaviors may be trans-culturally associated to masculinity (Galdas, Cheater, & Marshall, 2005; Lane & Addis, 2005). Mahalik, Lagan, and Morrison (2006) reported that American and Kenyan men's conformity to masculinity norms was positively associated with risky health behaviors and negatively associated with health protective behaviors such as looking for professional help (Mahalik, Lagan, and Morrison, 2006). Bowman and Walker (2010) observed that this phenomenon was also seen in Australian men and they suggested that conformity to masculinity norms was predictive of perceptions of barriers towards health care utilization. They concluded that the traditionally masculine male construct was an indicator of avoidance of health care and potentially a barrier to participation in cancer screening administration. They also noted that general self-efficacy was a moderator of the relationship between masculinity and perception of health care barriers. For the purpose of this research masculinity as a cultural construct is important since African American and West Indian American men may also subscribe to the reported masculinity norms as were reported since similarities were observed in some of their reported culturally based responses to prostate cancer screening and general health related behaviors (Ocho & Green, 2013; Wray et al, 2009; & See Pendleton et al., 2008).

In instances where treatment had been received, Burns and Mahalik (2008) suggested that the post-treatment physical adjustment of men needs to be better understood. In their work they established that emotional control is a major part of the masculine script. Masculine scripts pertain to "socially constructed ideals of masculinity

that constitute socially accepted ways of boys and men to think, feel and behave” (Burns & Mahalik, 2008, p. 56). For many men, according to Mahalik et al. (2003), remaining emotionally controlled is still an essential element of masculinity. This results from the vestiges of early social expectations that men must be tough, fearless, stoic and unwilling to express emotions. The consequence of adherence to this script includes unwillingness to discuss fear and mortality and bearing emotional distress in silence. Emotional control in men may also result in poorer post-treatment physical adjustment in men. Burns and Mahalik (2008) recognized an inverse relationship between emotional control and physical well-being and showed that higher emotional control demonstrated poorer physical well-being after treatment. Further, the study confirmed that more emotionally controlled men in all types of treatment situations demonstrated poorer well-being.

Discussions about male and female often revolve around physiological differences between the sexes and as a socio-cultural construct generated within various cultural settings. Therefore, men’s sense of their own masculinity includes a significant social construction and it is reasonable to hypothesize that masculinity impacts men’s experience of prostate cancer illness. When masculinity was investigated in its relationship to men with prostate cancer it was found that men diagnosed with prostate cancer felt a compromised sense of their own masculinity as a result of the disease (Chapple & Ziebland, 2002).

Men diagnosed with prostate cancer perceived their masculinity as impugned simply by seeking medical attention at the onset of symptoms of the disease (Chapple & Ziebland, 2002). Other meaning related aspects of their experience as reported by men included such things as: help seeking behaviors, incontinence as a consequence of the

disease, inability to work, and impotence, and these were considered by men to be compromising to their masculinity. Incontinence, for example, was perceived as compromising to masculinity since men are supposed to be in control of their bodies. They attributed similar meaning to work. Since work was a major source of status and identity, the lack of energy, which inhibits a man's ability to work, was seen as a compromise to masculinity. Impotence was also seen as a measure of inadequacy of masculinity and since hormonal treatment resulted in a reported lack of sexual desire and interests the treatment was seen as an inhibition to masculinity. These discoveries reinforced the notion that masculinity is socially and culturally produced. It also confirms the assertion that prostate cancer has a generally debilitating impact on men's concept of their own masculinity. The meaning attributed to the disease is relatively incapacitating and thus affords the need for investigative attention.

#### ***Other Possible Socio-Cultural and Psychological Issue - Fatalism***

Fatalism is conceptualized as the extent to which people feel that their destinies are external of their control. It often encompasses a religious dimension and a present time orientation (Guzman, Santiago-Rivera, & Haase, 2005). Guzman et al. (2005) noted that fatalism "may be a function of conceptualized cultural scripts and culturally significant assumptions on which a given group bases its thinking, feeling, and behavior" (Guzman et al., p. 6). Sue and Sue (1990) cautions that fatalism may be conceptualized differently by various cultural groups in that some people may perceive fatalism as external realities such as belief in chance, luck, religious beliefs, or political forces.



Two theories of fatalism are often presented they are: a) a deficit oriented theory which conceptualizes fatalism as a source of increasing psychological distress; and b) a resource oriented model which conceptualizes fatalism as a means of selectively coping with loss, diseases, sudden death, and crises that are beyond a person's scope of control (Guzman et al., 2005). For the purposes of this study fatalism is to be understood as a general belief that diseases and other destinies are beyond a person's control and the beliefs are often rooted in religious beliefs and an orientation that is focused only on the present. This orientation presents an obstacle to men engaging in health promoting behaviors such as PSA testing, DREs and doctors' visits.

### ***Men's Health Psychology and Health Issues***

Health psychology is better in helping to evaluate and address holistic health when it is attentive to the essence of well-being, concentrate on good physical health, and focuses on individual's good health and the social context (Marks, 1996). Simply focusing on illness and specific sickness related behaviors does not consider health in its relevant expansive context (Lee & Owens, 2002). The gendered approach to considering men's health focuses not only on harmful behaviors and the disease outcomes but focuses "on the influences on and determinants of these behaviors – the social constructions which influences individual men's behavioral choices and thus affect their health behaviors and outcomes" (Lee & Owens, 2002, p. 214). Men's health would, therefore, encompass their physiological state, their psychological well-being, and their social context. Utilizing men's health psychology from this perspective would include "normal physiological processes such as growth and aging...relationships between men and their

families; ... men's interaction with the wider society...and both positive and negative aspects of cultural notions of masculinity..." (Lee & Owens, p. 214).

Psychological distress occurred in men with prostate cancer at various points of the disease manifestation and treatment; at points of assessment, diagnosis, treatment, follow-up and recurrence of the disease (Balderson & Towell, 2003). Fears and anxiety exist in these men because of concerns about disease progression, their own disabilities, and dependency and possibility of their own death. Distress also is experienced because the methods of treatment for prostate cancer, surgery, radiotherapy and hormone therapy cause side effects such as urinary, sexual, and bowel dysfunctions. Mood swings, increased irritability, increased anxiety, and increased depression are also psychological hallmarks of men diagnosed with prostate cancer. Other unique psychological difficulties are the problems related to choosing between treatment options, uncertainties about treatment outcomes, and 'PSA anxiety' – the anxiety men experience while waiting to find out their PSA scores after treatment (Woods et al., 2006; Balderson & Towell, 2003).

Addressing prostate health of West Indian American men would need to move beyond their personal, subjective, and intra-individual causes of distress and disease and address their overall social context. Aspects of the culture that values them for their economic output must move on to emphasizing and honoring them for their capacity to form and maintain meaningful relationships. These culturally based health issues point to the additional relevance of cultural and social context of West Indian American men's health as it pertains to prostate cancer. Though the relationships between these men's choices, their behaviors - particularly ones pertaining to health, and their health outcomes

are complex, but it seems that these connections need to be explored in order to better understand the experience of prostate cancer screening decisions of West Indian American men and their partners.

As psychological variables were examined (Sieverding et al., 2010) it was recognized that certain psychological variables contributed to prostate cancer screening decisions. Of the evaluated psychological variables, more negative attitude and perceived low behavioral control were noticed in non-attendees of cancer screening examinations. These individuals also reported lower subjective norms and lower descriptive norms together with lower scores on behavioral intention with regards to participating in cancer screening examination. It was also noted that non-attendees to cancer screening examinations who reported high intentions to participate in cancer screening examinations demonstrated significant compliance with their intentions to participate in the cancer screening examination (Sieverding et al., 2010). Within the context of this study these findings are theoretically and conceptually relevant since positive or negative attitudes as well as intentions are related to compliance with cancer screening behaviors. These suggest that there is conceptual appropriateness in including these concepts in questions that probe at the subjective conceptual contributors to the experience of prostate cancer screening decisions and ultimate behaviors in men. Probing the conceptual range of this subjective reality may not be adequately addressed initially by a qualitative approach in this study. Therefore, to better get to the meaning of this experience will be initially done by a qualitative approach to understand meaningful experience of prostate cancer decision making between heterosexual West Indian American/African American men and their partners.

### *Quality of Life Issues Related to Prostate Cancer*

Prostate cancer screening can produce outcomes that may lead to differing decisions and actions by people who may be facing the possibility of prostate cancer diagnosis. The actions may include biopsy, treatment, and treatment complications (Cantor, Volk, Cass, Gilani, & Spann, 2002). The complications resulting from surgical and radiotherapy treatments include impotence, urinary incontinence, and bowel problems. The consequences of these complications are compromised quality of life and restricted life functioning capabilities. The results of these difficulties are a compromise in a man's self-image and sense of self and a challenge to the most intimate aspects of a couple's relationship. The quality of the relationship is related to the nature of the experience of the couple and this understanding again emphasizes the need for this study to clarify the experience of screening decision making.

There are differences between husbands and wives in their respective preferences for the outcomes for prostate cancer treatment and quality of life (Volk, et al., 2004). In general terms, husbands' evaluated their outcomes to be far worse than their wives' evaluations about husbands' outcomes. Wives seemed to have been satisfied with the quality of life experienced by their husbands and would not trade the quality of life for quantity of life even when incontinence and impotence were considered. On the other hand, husbands were willing to trade some quantity of life for quality of life if they were afforded the choices of the outcomes (Volk et al., 2004).

One to two years after diagnosis and treatment of prostate cancer both husbands and wives (about one half husbands and three quarters of wives) experienced some degree of psychological distress related to the cancer. Spouses of prostate cancer patients

are noted to experience greater psychological problems such as worry and tension and other somatic problems such as insomnia and fatigue than their prostate cancer-patient husbands (Volk et al., 2004). The psychosocial functioning of men newly diagnosed with prostate cancer particularly experienced impairment in psychosocial functioning. The impaired psychosocial functioning is recognized in lower vitality, unwillingness to engage socially, and lower mental health experiences. Fortunately, there was no noticeable increase in recognized psychiatric disorder nor adverse familial effects in their couple relationships (Love et al., 2008).

The diagnosed person and partners may have different views about quality of life experience after a man has experienced radical prostatectomy. Sexuality and intimacy have a profound effect on their differing perspectives. Radical prostatectomy is a procedure associated with high cure rates. However, it brings disruptive side effects that may persist for years after the procedure. For example, side effects include erectile dysfunction and urinary incontinence for most men for years after treatment (Perez, Skinner, & Meyerowitz, 2002). Though much attention is given to inability to attain an erection after prostatectomy, other pertinent sexuality impacting consequences of radical prostatectomy include disruption in desire, disruption in the orgasm phase of the sexual response cycle, and other aspects of sexuality - frequency of sexual behavior, satisfaction, body image, and concerns over sexual capabilities (Perez et al., 2002).

The need to expand the definition, meaning, and understanding of the construct of sexuality in order to adequately evaluate the effects prostatectomy has on the quality of life of prostate cancer patients is emphasized (Perez et al., 2002). These authors' contend that sexuality as a construct should include physical, behavioral, and cognitive

components as are often seen in the literature. It should also embrace a social dimension since it encompasses social behavior involving another person. A person's sexuality also plays important roles in psychosocial adjustments. Aspects of compromised psychosocial adjustment generated after prostatectomy are: poor adjustment, avoidance of sexual activity, and the in/ability to engage in daily living activities that relate to sexuality. The outlook on life is a dispositional matter noticed as individuals begin to view life negatively versus viewing life positively and this contributes to psychosocial adjustment and impact on sexuality. A final aspect of sexuality that is required in order to be comprehensive in the contextual understanding of the construct is the impact of the illness on others – patients' spouses. Partners' experience can be very distressing and invariably healthy partners are affected in a major way by the illness of their sick spouses.

Perez et al. (2002) observed that even as patients experienced significant erectile and urinary dysfunction these were not the variables associated with emotional distress and quality of life. Instead, "overall physical functioning" and "generalized expectancies for positive outcomes" were the significant predictors of emotional distress/well-being and quality of life. For example, being able to perform/non-perform daily activities could influence sense of in/dependence. Similarly limiting social and/or occupational contact could have similar effects. A person's mood after surgery and during recovery contributes to experience of wellness and dispositional optimism was established as a determinant of positive mood after cancer surgery (Perez et al., 2002).

The conceptualization of sexuality in a multidimensional manner was deemed to be an important aspect in helping to understand and experience better quality of life.

Andersen and LeGrand (1991) and Costa, Piedmont, Ponticas, & Wise (1992) asserted that the multifaceted understanding of sexuality and intimacy accounted for a modest proportion of patients' quality of life outcomes. They noted that sexuality should also be conceptualized in relationship and body image terms and that relationship adjustment and body image had the greatest predictive value for quality of life. Body image of itself has been found to be associated with personality relationship adjustment and sexuality (Andersen & LeGrand, 1991; Costa et al., 1992). The multidimensional aspect of sexuality is addressed as an important construct in understanding quality of life issues after radical prostatectomy. They also noted that the quality of the overall sexual relationship before the surgery is similar to the overall nature of the relationship after surgery (Andersen & LeGrand, 1991; Costa, Piedmont, Ponticas, & Wise, 1992).

### *Attempts to Create Meaning in Coping Experiences*

The attribution of meaning is again illustrated in couples' experiences of the illness in context of the family's individual family experience rooted in their cultural experience. The capacity of the persons in a dyadic relationship to cultivate meaning in a context of the experience of chronic illness is illustrated in their shared dyadic distress ((Badr & Taylor, 2009; Kim et al, 2008), their congruence coping (Berge et al., 2007; Fegundes, Berge, and Wiebe, 2012; & Revenson, 1999), and the cultivation of the experience of "we-ness" (Fergus, 2011). The concept of the shared dyadic experience captures the idea that spouses of diagnosed individuals also deal with stress attendant to events surrounding the cancer. In the shared experience there is a dynamic relationship in stress responses within a dyad in that the manner in which one member of the romantic

couple deals with the cancer is reflected or mirrored in the way the other deals with the cancer (Berg & Upchurch, 2007; Fagundes, Berge, & Wiebe, 2012). Their congruence coping is conceptually related and it is realized as the similarity by which both members of a dyad adopt the same coping strategy as they respond to the same stressful event (Revenson, 2003; Revenson, 1994; & Figueiras & Weinman, 2003).

The experience of “we-ness” occurs as couples go through a process of rupture and repair of their relationship and in negotiating their recovery three main themes seem to emerge: 1) Riding the Vortex; the coping and adjustment efforts utilized by the diagnosed couple in their dealing with the illness. 2) Holding the Communal Body intact; that which pertains to the relational resources and the deeper motivations, and capacities that are the underpinnings of the couple’s resilience that enable them to adapt in context of dealing with their adversity, and 3) Invincibility and its underbelly; a more pervasive concept that is the couple’s understanding of their relationship and their denial of their own mortality about their life and relationship and in their daily lives they maintain a deeper sense, assumption, and belief in the permanence of their marital union. (Fergus, 2011). Here again, the meaning of experience is illustrated and and this study seeks to better understand West Indian men’s perception of their own experience as they engage in prostate cancer screening decision making with their partners.

### **Men and Self-assessed Physical Well-being Following Treatment for Prostate Cancer**

A conceptually related phenomenon to quality of life in men is their emotional control and their self-assessed physical well-being following treatment for prostate



cancer. There are three basic types of treatment for men diagnosed with prostate cancer; surgery, radiation, and hormone treatment (American Cancer Society, 2005c). The main surgical option is radical prostatectomy, which involves the surgical removal of the entire prostate. Radiation options include external and internal radiation. The external beam radiotherapy generally involves high-energy x-ray or radioactive particles generated exterior to the body and directed at the malignant areas of the disease (Eaton & Lepore, 2002). Internal radiation brachytherapy involves the implantation of tiny radioactive pellets into the prostate (American Cancer Society, 2005c). Especially for men with metastatic cancer hormone therapies are often used. Antiandrogens are one such therapy; it involves a pharmacological measure that limits the production of androgen. Androgens are known to promote the growth of cancerous cells. Luteinizing hormone-releasing hormone analogs are utilized to inhibit the body's production of testosterone.

The dilemma facing men diagnosed with prostate cancer is that all therapies are known to have negative side effects, including: hot flashes, loss of muscle mass, erectile dysfunction, fatigue, rectal discomfort, diarrhea, urinary urgency and incontinence, breast enlargement, osteoporosis, and liver dysfunction (American Cancer Society, 2005c). Each treatment for prostate cancer has its unique side effects. For example, men with radical prostatectomy are 1.5 times more likely to experience sexual impotence than men elected to have external beam radiotherapy (Helgeson, Lepore, & Eton, 2006). Similarly, men who were treated with radical prostatectomy are more likely to report poorer bowel, urinary, and sexual functioning than those who selected brachytherapy (Soderdahl et al., 2005). The research suggested that surgical and hormonal treatments are associated with

more adverse side effects on men's physical functioning than the non-invasive procedure of brachytherapy.

### **Men's Responses to the Disease**

There are additional issues related to dealing with prostate cancer within the African American community that may be illustrative of how to deal with the West Indian American community since there may be some cultural similarities between the groups.. For example, the disposition of the family whether they were dominantly optimistic or pessimistic before illness contributed to their approaches in dealing with the disease (Taylor et al., 1992; Taylor,1983). Effective methods to promote and enhance screening for prostate cancer in the African American community have been proposed (Weston et al., 2007). Education, tailored behavioral interventions, health education addressing the enhancement of the quality of life of diagnosed men and their families are among the suggested methods of dealing with prostate cancer (Myers et al., 1999; Lubeck et al., 1999). The variability in the coping strategies of men of African heritage after they have been diagnosed with prostate cancer is also a concern. The coping strategies that were utilized included seeking or using social support, focusing on the positive, distancing, cognitive escape-avoidance, behavioral-escape avoidance, emotion-focused coping and problem-focused coping (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Volk et al., 2004; Lazarus & Folkman, 1984). The chosen coping strategies also seemed dependent upon the nature of the illness and the type of treatment needed for their specific disease presentation.

Management of the disease after its onset remained an interesting aspect of men's response to diagnosis with the disease and the manner in which families will be affected. For example, some men have difficulties disclosing to their partners, to the wider family circle, and to their work community about their disease problem (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). This response is probably linked to their notion of masculinity, conceptualized and experienced as culturally based ideology prescribing gender relations, attitudes and beliefs (Thompson & Pleck, 1995), is also a factor in the men's reactions to the disease diagnosis. Of course men's view on

Contemplating and understanding the functioning of the family in order to act to prevent or mitigate against the onset of prostate cancer or to intervene after the onset of prostate cancer has significant potential for helpful or harmful ways in dealing with the disease. This work is attempting to suggest the usefulness of family systems approaches in dealing with the disease by assessing the families, suggesting intervention strategies to aid in treatment options decision making, and coping strategies for diagnosed individuals and their families.

## **Potentially Effective Methods to Enhance Screening Decisions and**

## **Behaviors among West Indian American Men and their Partners**

### ***Education***

The benefits of education about prostate cancer among African American men were demonstrated by training using a computer assisted instructional (CAI) tool in the dissemination of prostate cancer information to men of African descent in Black churches (Weston et al., 2007). It was determined that through using this specialized means of

communicating and teaching about prostate cancer men of African descent demonstrated significant increase in knowledge and awareness about prostate cancer. A threefold approach was used: 1) exploiting the potential of the CAI as a tactic for reaching men of African descent, 2) using the Black church as a channel of information about prostate cancer dissemination, and 3) employing racial identity to facilitate acceptance of health-related messages. The results of this investigation suggest that the CAI considerably increased overall knowledge and awareness of prostate cancer regarding; a) risks of the disease, b) African American disparities, c) treatment options, d) disadvantages and advantages of screening and, e) the benefits of early detection. The study suggests that innovative education strategies will be useful in providing education about prostate cancer and affect treatment decisions for prostate cancer among men of African heritage.

Prostate cancer education and screening for early detection of the disease have been evaluated in other studies and the findings suggest benefits for the African-American community. For example, Myers et al. (1999) suggested that a tailored behavioral intervention can influence adherence to prostate cancer screening and early detection among African-American men. By investigating factors contained in the Preventive Health Model (PHM) it was discovered that numerous variables were positively associated with adherence to prostate cancer education and screening for early detection. The variables included the following: a) being older (over 40 years), b) having more formal education, c) being married, d) a history of benign prostate hyperplasia, e) having a recent early detection examination, f) awareness of population risk for prostate cancer, g) belief that prostate cancer can be prevented, h) interest in knowing whether one has prostate cancer, i) belief that early detection should be done in the absence of

symptoms of prostate cancer, j) belief in the salience and coherence of screening, k) belief in the efficacy of early detection of prostate cancer, l) perceived self-efficacy related to prostate cancer screening, m) family support for prostate cancer early detection, n) physician support for prostate cancer early detection, and o) intention to have an examination for prostate cancer. Concern about embarrassment about the examination was negatively associated with screening. Importantly, it was observed that success in providing PcA education is achieved best as the a method of communication or education strategy to which the men are most receptive is used (Myers et al.,1999; See Llic et al. 2007; & Williams-Piehot, McCormack, Treiman, & Bann, 2008).

Additional information on educational interventions seems to consistently support their value in enhancing quality of life of men with prostate cancer. The quality of life difficulties noticed in men with prostate cancer are disease specific problems such as urinary and sexual dysfunctions. There are also general life problems which revolve around diminished mental and physical functioning, difficulties in role functioning, well-being, energy levels, and reduced capacity to work. Education about these challenges may promote positive responses towards prostate cancer screening (Lubeck et al., 1999; Stanford et al., 2000). However, there is also evidence that while education alone may work, education combined with facilitated peer discussion contribute to improved quality of life of prostate cancer patients and similarly helps in fostering screening behaviors in men (Lepore et al., 2003). These educational interventions were demonstrated to have a positive effect on several pertinent outcomes such as knowledge about the disease, health behaviors, physical functioning, employment, and sexuality distress. Education combined with facilitated discussions resulted in more stable employment, more positive health

behaviors, and diminished bothers from sexual dysfunction. Compared to a control group, two groups with education only interventions and education plus facilitated discussions reported better physical functioning.

These educational interventions seem to have a more marked effect on the improvement of the quality of life of men with less formal education than it had on men with college education and beyond. While it is fair to assume that men with more formal education have more available resources at their disposal to deal with these health problems and that they may be more proactive in seeking out information to deal with prostate health issues, this is still an important finding. It suggests that educational intervention may be a very important source of help for lower educated and lower socio-economic status men (Lepore et al.).

### ***Psycho-educational Intervention***

The benefits of psychoeducational interventions were also assessed for men with localized prostate cancer (Helgeson, Lepore, & Eton, 2006). Two personal resource variables were assessed; self-esteem and self-efficacy. They were assessed in interaction with the interventions of educational and educational plus group discussion to determine the interventions effects on both general and prostate specific quality of life. The investigation determined that men with low self-esteem were buffered from poor physical functions when they were exposed to both forms of intervention as contrasted to controls that were not buffered from the effects of low self-esteem. Similarly, it was determined that the interventions were providing a buffer against low mental functioning for men with low self-esteem as contrasted to the effect of low self-esteem on the controls. Self-

esteem interaction with depressive symptoms indicated that men with low self-esteem were buffered from the higher effects of depressive symptoms when they were exposed to the interventions. Low self-esteem was related to worse prostate-specific functioning (urinary functioning, sexual activity, and bowel functioning) among the controls but not among the intervention groups. Similar patterns were noticed for self-efficacy and depressive symptoms in men with prostate cancer controls versus those who experienced the interventions. The findings suggested that men in this study with lower levels of overall self-esteem, lower levels of prostate-specific self-efficacy, and higher levels of depressive symptoms benefited most from the interventions.

Another variable that contributed to dealing effectively with diagnosis of prostate cancer is the immediacy or lack of immediacy of diagnosed persons'/families' decision-making about treatment options. Education again appears to provide a benefit to the decision makers. Older men seem to make more immediate treatment decisions than younger men (Meyer et al., 2007) and this is in contrast to the longer time on task generally observed in older adults (Salthouse, 1996). Three explanations are presented for this phenomenon. First, older adults have limited cognitive resources (Park, 1999; Salthouse & Babcock, 1991) and the immediate decision reduces the cognitive overload related to making a treatment decision (Berg et al., 2004). The second explanation is the greater knowledge and experience of older adults. They have become more expert in their life and health issues and are better able to process complex information (Meyer et al., 2007). The third reason older adults make decisions quicker is because of different cultural and social influences affecting them in contrast to the younger generation. Younger people, it is posited, are more informed and more dynamically interacting with

current information and have had a proclivity to be more involved in the decision making process in dialogue with their doctors. Older people, on the other hand, were more inclined to be non-participatory in decisions about their health and were more quickly responsive to doctors' recommendations about treatment. Educational and psychoeducational interventions, therefore, seem to have positive impact on responses to prostate cancer and enhancing the quality of life of men with prostate cancer. In attempting to help men at risk for the disease these educational/psycho-educational option should always be an important opportunity to be utilized in service to the studied population.

### **Coping Strategies of Men Diagnosed with Prostate Cancer**

Coping is understood as a process in which cognitive, affective/emotional, and behavioral responses are used to deal with events that place a demand on one's resources" (Kudajie-Gwamfi, Consedine, & Magi, 2006). Coping takes many forms but the main forms of coping researchers have focused on are "emotion-focused" and "problem-focused" coping (Dunkel-Schetter, Folkman, & Lazarus, 1987). Problem focused coping can be defined as cognitive and behavioral approaches directed at and intended to actively solve problems with the hope of reducing tensions and stress in the process. On the other hand, emotion-focused coping refers to strategies that are not focused on changing any specific thing about the problem but are cognitive and behavioral interventions that are attempting to help individuals adjust to stressful situations (Folkman & Lazarus, 1988; Brantley et al., 2002). Though there may be differences in the classification of coping strategies (i.e. determining which is emotion-



focused versus problem-focused style of coping) it is generally agreed that these two definitions have conceptual utility value.

Appropriately assigned to either category of coping are eight ways of coping as suggested by Lazarus and Folkman (1984). There are two forms of problem-focused coping; planful problem solving, and seeking social support. There are seven forms of emotion-focused coping; distancing, self-controlling, accepting responsibility, escape/avoidance, confrontive coping, positive reappraisal and seeking social support. Seeking social support is common to each type of coping, hence a total of eight strategies. Kudajie-Gwamfi et al. (2006) suggest that these two forms of coping demonstrate variability as a function of context. The context includes the thing that is being coped with, culture, scope of the information needed to facilitate coping, and the nature of the stressors being dealt with.

Dunkel et al. (1992) studied a large sample of persons diagnosed with illnesses and evaluated their coping strategies. They established from their study that five patterns of coping were identified: 1) seeking or using social support, 2) focusing on the positive, 3) distancing, 4) cognitive escape-avoidance, and 5) behavioral escape-avoidance. This finding, they affirmed, were similar to findings discovered earlier in investigations involving smaller samples of cancer patients. They posited that these coping strategies may be universal and not limited to cancer patients. They further observed that cancer patients did not usually report using one coping strategy but usually used multiple coping strategies.

Distancing was the most common form of coping in the and it was negatively associated with education but was unrelated to other variables in the study. The

remaining forms of coping were used in varying proportions depending on the individual characteristics of the persons with cancer and their current appraisal of their situations. Persons' appraisal of the cancer, particularly appraisal of the degree of stress which may result from the cancer was a predictor of three forms of coping: seek and use of social support, cognitive escape-avoidance and behavioral-escape-avoidance. It stands to reason that these coping styles will be seen in prostate cancer victims and assessing coping patterns among prostate cancer victims should contemplate these patterns (Dunkel et al., 1992).

Prostate cancer diagnosis or the threat of prostate cancer diagnosis may activate a range of potential coping styles and motivate responses to screening for prostate cancer and other health promoting behaviors and/or health defeating behaviors pertaining to the disease. For example, diminished quality of life, impotence, incontinence, and/or death or the threat of any or all of these may effectively encourage coping strategies that cover the gamut from one extreme to the other of emotion focused and problem-focused coping (Visser et al., 2003; Volk et al., 2004). The suggestion is that the threat of prostate cancer may promote diligence in screening activities among one group of men or it may promote avoidance and poorer screening habits in another group of men.

Coping strategies may also differ after the diagnosis of prostate cancer. It has been demonstrated in studies that problem-solving, self-reliance, social support, distress, wishful thinking, avoidance, and self-blame are often the strategies of choice by persons diagnosed with prostate cancer (Kudajie-Gwamfi et al., 2006; Ben-Tovin, Dougherty, Stapleton, & Pinnock, 2002;). Evidence suggests that coping styles with illness, racial stressors, and care-giving may differ among African-American, Hispanic, and Caucasian

men (Brantley, O’Hea, Jones, & Mehan, 2002). For example, it is reported that among men with HIV/Aids African-American men reported more use of positive reappraisal than Caucasian men (Heckman et al., 2000). Among low income African-Americans and Caucasians, African-Americans appeared to use more positive reappraisal and distancing more often than Caucasians (Brantley et al, 2002). It is also noted that low-income individuals have been shown to employ all the coping strategies as defined by Lazarus and Folkman (1994) significantly more than the higher income sample.

The process of coping with radiation therapy for prostate cancer was examined by Johnson et al. (1989) and they determined that self-regulation played an important role in coping. Self-regulation theory has a central concept of schema. It asserts that schema guides the organization of incoming information, retrieval of said information, goal directed behavior, and focus of attention (Thorndike & Haynes-Roth, 1979). It was hypothesized that exposure to a particular type of preparatory information would facilitate patient’s coping outcomes. In the instance of radiation therapy (RT) the information must provide the patient with concrete objective information about the four stages of their RT treatment and experience. The four stages of RT are: a) treatment planning sessions, b) beginning of treatment, c) onset of side effects, and d) decline of side effects. RT treatment results in “emotional responses” and “disruption of usual activities” (Johnson et al.). The presentation of information covered such topics and descriptions of such items as a) physical sensations experienced by most people who experienced RT (specifically concrete in such modalities as things seen, heard, felt, smelled, and tasted), b) the environmental features of the experience and c) the duration of procedures, experiences, and events surrounding RT. It was discovered that patients’

understanding of their experience together with a reduction of the discrepancy between their expected experience and their actual experience enhance their coping abilities. The two elements in the self-regulation process were ‘understanding’ and ‘reduction of discrepancy between actual and anticipated experience’ played crucial mediating roles in the problem-solving aspect and the maintenance of usual activities in radiation therapy treatment. However, understanding seemed to play a more important role in regards to patients being able to maintain usual activities during and after receiving radiation therapy. This finding support the importance of detailed information presentation to patients to enable the formation of a schema which can be activated to facilitate coping with a stressful event; in this instance prostate cancer, screening, treatment, and recovery.

In instances of married men and their spouses, collaborative coping (spouses pooling resources and jointly engaging in problem solving) has been determined to be an effective coping strategy (Berge et al., 2008). Collaborative coping, for example, was observed to be associated with some significant results within the dyadic relationship. First, collaborative coping was associated with same day positive emotions. Second, collaborative coping was positively associated with both husband’s and wife’s perceptions of coping effectiveness. Third, particularly for wives in their study collaborative coping was inversely related to negative emotions; the higher collaborative coping the lower was negative emotions. Fourth, for both husbands and wives, the more each person reported using collaboration in making daily household decisions the more they reported spousal involvement in their coping with stress. Fifth, collaborative coping was associated with marital satisfaction for both partners in the marriage. These findings suggest that collaborative coping provides significant emotional benefits to partners in a

marital relationship who are dealing with illness. Observed in this study is the fact that collaborative coping was used more frequently when relationship quality was high and when individuals engaging in the collaborative coping during the illness demonstrated a historical pattern of collaborative decision making (Berge, et al., 2008).

Variability in coping among caregivers is also established as occurring in variable ways between different racial and ethnic groups. Adams, Aranda, Kemp, & Takagi (2002) reported that Hispanic caregivers demonstrate more avoidance than African-American, and Caucasian caregivers. Also, African-American and Hispanic caregivers utilize religious coping more often than Caucasian caregivers. In instances when they are confronted with racial stressors, African-Americans have been shown to react more frequently with anger to the racial stressors than their Caucasian and Hispanic counterparts (Also see Kudajie-Gwamfi et al 2006).

The evidence seems to consistently show that there is also variability among men in their coping with prostate cancer. Coping differences are as follows: 1) avoidance of disclosure of the disease and minimization of illness threat are noticed more in Caucasian men in contrast to African-American men (Gray, Fitch, Phillips, Labrecque, & Fergus. 2000), 2) religious coping differentially predicted health outcomes among men of Caucasian versus African-American men 3) there are significant ethnic group differences in coping styles between groups of more specifically defined ethnicity within the USA - the differences are manifested in PSA test frequency; test frequency increases with regards to length of stay in the USA for immigrant groups, 4) problem solving as a coping strategy showed a positive relationship with PSA testing across all ethnic groups in this study, 5) prayer, avoidance, and wishful thinking as coping styles were not

associated with PSA test frequency, and 6) coping styles differentially predicted test frequency across ethnic groups (Kudajie-Gwamfi et al., 2006).

This pattern of variability of coping styles among men of various ethnic groups requires closer attention. Probably, hidden in this phenomenon are details that may be exploited to enhance screening, early detection, taking advantage of treatment, improvement of longevity, and development of better coping strategies for non-diagnosed West Indian American men and their diagnosed counterparts.

### **Summary Statement and Rationale for Research Focus**

An overview has been presented of the multiple issues that are associated with West Indian American men and their experience of prostate cancer screening decision making between heterosexual West Indian American men and their partners. A case was made to illustrate the severity of the incidences and prevalence of prostate cancer within the African American and West Indian American Communities. The apparent concerns range from awareness/lack of awareness of the threat of the problem of prostate cancer within that segment of the population, socio-demographic issues, familial history, genetic history, environmental issues, and multiple culturally based subjective realities that are implicated in screening experiences and screening decisions. These culturally based issues include masculinity and its attendant effects, fatalism, the coping strategies of the men and their partners in instances of diagnoses, and the responses of men and their partners to educational, psycho-educational and psychotherapeutic interventions. The possible role of meaning making that may be done within the community was also addressed.

There is a paucity of literature that addresses the experience of prostate cancer screening decision making of heterosexual West Indian American men and their partners. The literature that addresses African American men and their partners was also addressed since there was a suspicion by the writer that there may be some cultural, racial and genetic similarities between these groups. However, there appears to be a significant gap in the current literature and there seems to be nothing that addresses the unique meaning of the experience of prostate cancer screening decision making of this population of men and their partners. Because prostate cancer is such a threat to this significant segment of the population with particular effects on their family functioning and marital experience, there is need for research to carefully investigate this experience. The result of this investigation could include the generation of ideas, from a family systems perspective and family health psychology standpoint, that may be helpful in enhancing the experience of screening decisions while simultaneously enhancing family functioning and family relationships. That is the focus of this research. The hope is that at the conclusion of this study the knowledge generated will better enable family theorists and therapists to better understand the meaning and the experience of prostate cancer screening decisions among heterosexual West Indian American and African American men and their partners.

## CHAPTER FOUR

### THEORETICAL OVERVIEW OF STUDY

Qualitative research is generally understood as a discovery-oriented analysis of verbal texts in which there is an intensive study of a smaller group of people that is studies\|d in quantitative research. The methods used in qualitative study are of three basic kinds (Rennie, 2012). First, there is the conceptualizations of the meanings of experiences achieved either through the analysis of participants reports or through inferences from observations of their behaviors; this method is often referred to as the experiential kind of qualitative research (Glasser, 1978; Glasser & Strauss, 1967; Strauss & Corbin, 1998). Second, the analyses of conversations and discourses, in which people's use of language, conversations, and their patterns of daily interactions are analyzed; often referred to as the discursive kind of qualitative research (Garfinkel, 1967; Silverman, 1998; Ibanez & Iniguez, 1997). Third, there is thematic analysis in which there is applied to either experience or discourse in which the themes of experience or discourses are parsed and examined; often referred to as the experiential/discursive kind of qualitative work (Braun & Clarke, 2006; Elliot, 2002; Frommer & Langenbach, 2006; McLeod, 2006).

The grounded theory approach seeks to build a theory from data (Corbin & Strauss, 2008; Berg, 2006) or seeks guidance from a particular theory to formulate a research or to guide the research (Yin, 2003) and also attempts to generate a theory (grounded theory) or to follow a trend of helping to develop a pre-existing theory after research is done (Berge 2007). In such instances of the grounded theory approach, theory can be uncovered and/or be made more up-to-date after data collection and interpretation



of data. Qualitative research in its various forms seem to have increasing promise and use in the fields of family science, psychology, and in other social sciences (Rennie, 2012; Daly, 2007; Fern, 2001). The use of a theoretical framework as precursor to research or as a theoretical basis to build or improve theory is particularly salient when using grounded theory.

This current work is a qualitative study that sought to use focus groups interviews as a stand-alone and or part of a triangulated process (Berg, 2007) to help understand the experience of prostate cancer screening decision making among heterosexual West Indian American men and their partners. In the utilization of the focus groups there was an attempt to utilize important group interaction in discussions about prostate cancer screening decisions to help identify the tendencies and patterns of perceptions about the topic and to help promote self-disclosure among the participants (Daly, 2007; Krueger, 1994). It also sought to simultaneously detect, through the discussions, participants' conscious and unconscious responses and understandings, cultural proclivities, sociocultural traits and psychological processes, and attitudinal tendencies around the issues of prostate cancer screening decision making (Berge, 2007; Krueger, 1994).

While in the use of focus groups in contrast to grounded theory approaches there is not typically a theoretical perspective that guides the qualitative research or a theory that is generated in the process, there are rare cases when a theoretical guidance helps in the formulation of the focus groups approach. Not only may a theory guide in the question formulation but a theory can be useful in the rare instances of “theory applications” or when used in conjunction with “effects application” (Fern, 2001). There are instances of “theory applications” in which the understanding of phenomena is

necessary in order to be able to generalize beyond the applications that are being studied. For example, this research on the experience of heterosexual West Indian American men and their partners' prostate cancer screening decision making may uncover certain patterns and aspects of the experience that they routinely utilize; this represents theory applications. On the other hand, with "effects applications" as the aim of the research, a researcher may have little or no interest in generalizing beyond the population sector being researched. For example, the researcher may simply be interested in how the particular group (in this instance heterosexual West Indian American men and their partners) experience a particular decision making process.

This research was primarily an effects application approach that sought to create new ideas, collecting data that sought to understand unique thoughts of participants, identifying the needs, expectations, and peculiar experiences of the focus groups' participants and exploring the results of the focus groups responses. Initially, however, the focus groups questions and direction were guided by the theoretical perspective of symbolic interactionism in order to help generate an understanding of the meaning the participants attribute to their experiences in the decision making process. The theoretical guidance was utilized in the formulation of ideas for the questions and in offering direction of the study. The theory, however, did not drive the use of the data it rather guided in the conceptualization of meaning as expressed by participants.

### **Theory and a Rationale for Theoretical Framework in Study**

As is generally expected in academic research there is an attempt to build on general ideas inferred from different instances or observed occurrences or conceptual

frameworks in order to aid us in understanding and explain data (Bengtson et al., 2005). This process seems to work better when it is guided by theoretical underpinnings. A theory predicts or explains complex processes that illustrate causal relationships between and among concepts (Fletcher & Sarkar, 2013). Often a theory articulates interrelated propositional statements that attempt to describe how variables are correlated to each other (Bengtson et al., 2005). A clear theoretical understanding that suggests how a set of propositions are systematically related and are empirically testable (White & Klein, 2008) helps to guide a thoughtful approach to propose relationships between concepts. In this instance of qualitative research it helps the researcher surmise about possible contributors to the family experiences. The contributors to experience may be rooted in family interactions, cultural norms, beliefs, and values, and the meaning attributed to stories, words, and actions over time. An appropriate theoretical framework that guides the thinking of the researcher can help to explicate details about familial experiences regarding prostate cancer screening decision making. The theoretical framework that guided the thinking of this research is symbolic interactionism.

### *Family Systems Thinking*

Within a family systems framework there are numerous issues associated with prostate cancer that affect diagnosed persons and families. Family systems theory proposed that all family members' behaviors are practiced in a social-relational-context with an attempt to ensure that family members' basic need for order, security, belongingness, and identity are satisfied (Almagor & Ben-Porath, 2013; Minuchin, 1974). This understanding of the family system suggests that the need for the system functioning

with integrity becomes vitally important for the persons within the families. Important family resources such as security and support are supplied by the system and in the adequately functioning system such things as communication, meaningful attachment, sense of control, experience of status, are all experienced by family members. If these essential system functions are denied attempts are made by family members to regain control and retain homeostasis (Haley, 1976; Madanes, 1981, 1984).

An essential tenet of family systems theories, therefore, is that the family is an integrated whole or system functioning as a unit. More specifically, understanding the experience of prostate cancer screening decisions in heterosexual Caribbean American men and their partners involves an understanding of the meanings they generate in their multiple interactions with their communities. An investigation done from a systemic perspective may enhance understanding of the prostate cancer screening decision making experience and may also uncover systemic approaches or strategies that may contribute to behaviors that lead to timely and effective screening for the disease, afford early detection of the disease, and provide for early intervention when necessary. Systemic strategies may also generate preventive health behaviors and better overall health maintenance with respect to prostate cancer.

In general terms systems thinking involve a particular understanding of the person and a systemic thinking is often referred to as attentiveness to internal family systems (Schwartz, 1995). The family systems model offers an approach that emphasizes interpersonal and dyadic process occurring with familial relationships (Magnavita, 2013) that asserts the inclusion of the whole family in consideration of family challenges. This model conceptualized “pathology” not as an issue that occurred at a micro-level within

the mind of a single individual but rather conceptualized it at least in part as a dynamic interaction between the individual and the rest of the family system. Family system offered an understanding of families and their functioning with their unique interactional patterns as the bases for more functional behaviors and also the bases for the so-called pathological patterns within families. The non-functional or harmful behaviors were not seen as private intra-psychic challenges of only the individual family member but a function of the inter-relational patterns of the families (Magnavita, 2013).

The family system itself functions within a larger ecological system that impacts the family's strengths, weakness, systems of interpretation and responding to challenges that they experience (Tuge, Makrova, Hatfield, & Karnik, 2009; Bronfrenbrenner, & Evans, 2000). This wider model seeks to explicate the factors influencing families as being unique for families of particular racial or ethnic contexts. For example, African American families as a group have been adversely affected by a social environment that fostered structural racism during their chaotic history. Structural racism can be defined as "ways in which history, ideology, public policies, institutional practices, and culture interact to maintain a racial hierarchy that allows the privileges associated with whiteness and the disadvantages associated with color to endure and adapt over time" (Aspen Institute, Roundtable on Community Change, 2005, p. 50). This family systems model and the wider societal systems model of understanding help to clarify the idea that the wider societal system is in a mode of affecting the family system as a multifaceted mutual and shared interactions between people and their environment. This interaction is often referred to as "proximal processes" which lead to outcomes of competence and dis-functionality (Kelly, Maynigo, Durham, & Wesley, 2013). The family systems model,

therefore, offers a perspective of the family as an interactive unit in which members are constantly being influenced by each other while the family unit is also being constantly impacted by the societal environment in which the family continually functions and operates.

The internal family systems model allows the therapist to engage in systemic thinking about every aspect of the human existence – intra-psychic, familial, community, cultural, and societal. Concepts and methods utilized to address families' and individuals' challenges are attentive to the ecological issues that pertain to families/individuals. There is consideration, understanding, respecting, and utilizing of all networks of relationships pertinent to the presenting problems. All distress is considered as having an ecological context that alleviates the stress on an individual and/or dissipates stress to the interconnecting systems. In this context experiences and decision making about change attempts are always affected (Schwartz, 1995)

Human systems thinking insist upon the understanding that humans are gifted with certain innate drives and possess wisdom about their own health and welfare. Not only do they strive to maintain steady states they also react to feedback and seek creativity and intimacy. In instances of distress the assumption is made in systems thinking that people are deprived from their capacity to adequately access their wisdom and internal resources. Systems thinking seeks to help people to release constraints and better access their resources. Balance, harmony, leadership, and development are important principles in systems thinking. They offer options for intervention in the system to engender creative change and modifications in families (Schwartz, 1995; Goldenberg & Goldenberg, 2008).

A basic understanding of the family in systems terms is an important step in the overall conceptualizing within this systems framework. Understanding the family is almost a beginning point of this approach. It requires knowing that the family and individuals within a family are part of a system that is integrated and interrelated. The family may be conceptualized as “an ongoing, living system, a complex, durable, causal network of related parts that together constitute an entity larger than the simple sum of its individual parts” (Goldenberg & Goldenberg, 2008, p. 403). The dynamic and interactive realities of the systems approach seem to be congruent with the concepts of symbolic interactionism as a theoretical overview in understanding West Indian American Families and their ways of making meaning and experiencing their decision making processes regarding prostate cancer screening behaviors.

### **Symbolic Interaction Theory**

In attempting to understand the experience of prostate cancer screening decisions in heterosexual Caribbean American men and their partners, symbolic interactionism seems to be one theoretical framework that can inform focus group questions formulation and help to discover meaning in the experience. Symbolic interactions theory (SIT) focuses on the associations between symbols or shared meanings and interactions generated by verbal and nonverbal actions and communications. It is a framework for understanding how human beings engage in relationships with each other (LaRossa & Reitzes, 1993). People are seen as employing their reasoning and symbolizing capacities as they, with great rapidity and flexibility, conduct their tasks of interpreting circumstances. People are also constantly adapting to the interpreted situations based on

how they interpret the conditions they encounter. Symbolic interactionism subscribes to the idea of conscious thought as guiding actions and denies the occurrence of purely programmed behavior. Further, symbolic interaction proposes that people have influence on each other and that they contribute to each other's intrinsic humanity. It insists that there is a significant role of culture, symbols, and meaning systems in generating and changing human behaviors. In accentuating meaning, symbolic interactionism particularly emphasizes the meaning of the self and the manner in which the self is created through the interaction with others (LaRossa & Reitzes, 1993; Leeds-Hurwitz, 2006; Kanter, 1976). The theory asserts its relevance in the operation within the arena of everyday life enabling people to work out their relationships through reciprocal interpretations and adjustments in face to face encounters (Leeds-Hurwitz, 2006; Kanter, 1976).

### ***Thought Leaders of Symbolic Interactionism***

It is proposed that there are numerous intellectual antecedents to the current understanding of symbolic interactionism and suggested that along the course of SI's development there were selections of the key ideas from multiple contributors (Fisher & Strauss, 1978; LaRossa & Reitzes, 1993). The selecting process was analogous to purchases from an auction house of significant ideas (Fisher & Strauss, 1978). Some of the contributors to symbolic interactionism include noted personalities: Adam Ferguson, David Hume, and Adam Smith - eighteenth century thinkers; Johann Fichte, Freidrich von Schelling, and George Wilhelm Fredrich Hegel - nineteenth century thinkers; Josiah Royce, Charles Pierce, William James, and John Dewey – early twentieth century



American Pragmatist; Charles Horton Cooley, George Herbert Mead, and W. I. Thomas – also trained in the tradition of pragmatism. Symbolic interactionism was used as a framework for the scientific study of the family at the time of the early twentieth century. (LaRossa & Reitzes, 1993). Blumer (1969) noted that “symbolic interactionism is a distinctive approach to the study of human life and human conduct” (Blumer, 1969, p. 1) and declared that the contributors to symbolic interactionism (SI) studied and viewed human group life in a way that was consistently similar (Blumer, 1969).

George Herbert Mead (1959) laid the foundations of Symbolic interactionism in the early twentieth century. He extrapolated from John Dewey’s pragmatism and argued that human beings go through a constantly changing process and adaptation in a dynamically changing social world. He suggested that within the existing human mind the contemplation of situations enables the constant change that occurs in relationships (Jeon, 2004). Herbert Blumer (1969) built upon and elucidated Mead’s work and in the process built upon Mead’s philosophical concepts and established symbolic interactionism as a sociological theory and a unique approach to doing research. The emphasis of symbolic interactionism is, first, that the researcher needs to explicate the process by which meaning is developed and the nature of meanings that are represented in the interactions between or among human beings. The second idea is that meanings are understood only through interactions (Jeon, 2004). Concepts such as human society, social interactions, objects, actors, action, and the interconnection among actions are considered the root images upon which symbolic interactionism is built (Jeon, 2004; Blumer, 1969).

Charon (2009) suggested that there are five central ideas that define symbolic interactionism that are necessary to understand before dealing with the specifics of the theory. First, we have an obligation to understand the human being as a social person. The ongoing constant lifelong social interaction leads us to practice the behaviors we practice. Second, the human person must be assumed to be a thinking individual. Human actions are not just the result of interactions between individuals but they also result from internal interactions within the person; these are the thinking aspect of the being. Third, humans do not sense their environment directly rather humans “define the situation that they are in” (Charon, 2009, p. 28). Even though an environment exists it is the definition that humans attribute to the environment that is important. The meaning is the result of continuous social interaction and thinking. Fourth, human action results from the things happening in our present situation. “Cause unfolds in the present social interaction, present thinking, and present definition” (Charon, p. 28). The occurrences happening in the present time are of significant importance in human actions. Fifth, human beings are described as is lively and dynamic beings in an interactive relationship with their environment. Symbolic interactionism does not seek to utilize such words as “conditioning, responding, controlled, imprisoned, and formed in describing human beings (Charon, 2009).

This understanding stood in contrast to some other social-scientific perspectives in that humans were not conceptualized as passive agents but were seen as actively involved in whatever they do. Charon’s (2009) insistence is that for human actions to be understood one has to focus on social interaction, human thinking, definition of the situation, the present, and the active nature of human beings. These five ideas form the

outline for understanding the perspective of symbolic interactionism on understanding human beings. More importantly, this understanding of human being have applicability to West Indian American men and their partners as they engage in the experience of prostate cancer screening decision making. This perspective suggests that as West Indian American men and their partners engage in decision making they are active agents in their behaviors. Their actions, however, are influenced and guided by their lifelong interactions, their own internal thoughts, a constant defining of situations, while they have a continuous present focus. Their decision making experiences are influenced by these internal and interactive mechanisms. This seems to be offering important outlines for understanding this population's experience and decision making.

### ***Main Theoretical Concepts of Symbolic Interaction Theory***

A more detailed clarification of symbolic Interactionism (SI) observed that the way in which one defines or understands something will guide one's behavior in relation to it (Blumer, 1969). Accordingly, cognitive processes related to any catastrophic or chronic illness and a marital or dyadic relationship and how people perceive or process information pertinent to the two realities are relevant to behaviors and decisions related to the disease condition. Symbolic interactionism provides a useful framework for analyzing how people define and act in relation to marital relationships and chronic illness and/or catastrophic illness. The theory has been used to explore the familial context and attempted to explain various family processes including gender role negotiations, parenting, and intimate violence (Ehrensaft, 1985; Harris, 2001; Wolf-Smith & LaRossa, 1992). However, analysis of how people behave towards a catastrophic/or chronic illness

within a relationship and make health related decisions as the diagnosed person or the spouse or intimate partner of the diagnosed person has not been broadly done. Because it has not been done on this population dealing with the issues of prostate cancer screening decision making there is opportunity for this researcher to be guided into the creation of knowledge for this sector of the population. Finding a model that guides the thinking about methods to enhance screening decisions will be a useful outcome of this research.

### **Symbols**

Symbols are a basic building block of symbolic interactionism and it is to be understood as the bases upon which people abstract from the physical entities. A symbol is the medium of thought and communication that are used to represent the meaning of an entity. Within the theory a discrete piece of meaning is a symbol. It “is any sign that conveys meaning: language, gestures, rites, dress. Just as meaning is not innate to an entity, a symbol is not innate to a meaning” (Schneider, 2011 p. 251). While they are discrete building blocks of symbolic interactionism symbols are subject to change a change resulting from the social interaction and social construction of humans. This is another useful and instructive aspect of the theory in guiding the present research. The meanings attributed to experiences, disease possibility, screening behaviors can change over time and as such researchers and interventionists of various types can utilize strategies to engender changes in meaning within the West Indian American community (Charon, 2009).

Meanings of things and the symbols that refer to them are socially constructed and shared and the communication that individuals engage in is actually the exchanging

of symbols. Examples of symbols include body gestures, speech, written language, facial expressions, and gentle touching and they are all media to convey meaning (Schneider, 2011). Symbols, additionally, according to Schneider (2011), have some identifiable properties. In context of this study this understanding of symbols offer added opportunity and avenues to seek better understanding of the experience of prostate cancer screening. First, symbols stand for something (meaning), they are constructed objects that, as social products, are real entities. Contextually, therefore, prostate cancer, screening behaviors, screening decisions, and other health related behaviors can be addressed with a full set of meanings attached to them as symbols, social products or real entities. Second, they are intentionally used in conversations to produce responses. In a related sense the terms related to the prostate cancer screening decision making experience can be used to deliberately evoke responses in the individuals addressed in the study. Third, significant symbols ideally arouse a similar response in the person who employs them and the person who perceives them. Here is where the researcher and interventionist would need to take care to communicate with ethos and pathos to the more delicate aspects of the experiences surrounding prostate cancer in a manner that evokes emotional responses in the participants. Fourth, if we use symbols to assess, communicate, and construct meaning we construct and reconstruct culture (Schneider, 2011). Here again the researcher and interventionists would need to be attentive to their role in creating an updated culture that is effective in affording change within the community of West Indian American men and their partners. In the sharing of meaning through their respective symbols one engages in sharing culture and culture simultaneously is the basis for the sharing of symbols and their meanings.

This articulated viewpoint on symbols suggests that the meaning of the symbol is addressed through the interactionists' understanding of "reality." Reality is social and human understanding of what are seen externally and internally is developed through interactions. Objects which exist in physical form are "pointed out, isolated, catalogued, interpreted, and given meaning through social interaction" (Charon, 2009, p. 45) by humans; objects are understood as "social objects" Objects are defined by humans as they are given names. Ultimately a social object is "any object in a situation that an actor uses in that situation. That use has arisen socially. That use is understood and can be applied to a variety of situations" (Charon, p. 46). Words, however, are the most important symbols utilized by humans and they serve to make human thinking possible (Charon, 2009). Within this research, as focus groups are utilized the overall idea is to get participants to respond in words and to focus on their words to help understand and create the meaning of their experiences in relationship to prostate cancer decision making experience.

### **Families as Social Groups**

The proposition that "families are social groups" is a contribution of symbolic interactionism to the study of families. The assertion that individuals conceptually build perceptions of themselves and their identities through social interactions thereby enabling them to independently assess and assign value to their family activities also originates from symbolic interactionism (Leeds-Hurwitz, 2006). Families are, therefore, socializing selves and interacting groups with a shared sense of the world; a shared set of goals, values, beliefs, and norms. They also experience unique processes by which their symbolic realities are cultivated and established. People develop their self-identity by

internalizing the appraisal of others, particularly their family members. There is also a link between a person's self-concept and the manner in which a person thinks he/she is being perceived by others which is mediated by the target person's conceptualization of the perceivers' appraisal of the target person (McNulty & Swann, 1994). Leeds-Hurwitz (2006) observed that relationship building is also elucidated through the understanding of symbolic interactionism in that "the character of relationships is built moment by moment, by interactants, in and through interaction" (p. 236). In context of these features of symbolic interactionism key questions are generated from this theoretical framework. The questions that symbolic interactionism propose to answer resonate with a study that attempts to better understanding the experience of prostate cancer screening decisions in heterosexual West Indian American men and their partners.

### **Interrelationships of Screening Decisions Questions and Questions of Symbolic Interactionism**

LaRossa and Reitses (1993) articulated that symbolic interactionists are interested in are interested in probing useful questions for understanding families and their functioning. They are usually concerned about how family members arrive at a similarly shared sense of the world combined with how such realities as geography, race/ethnicity, class, gender, age, and time relate to family groups. This research seeks to inquire how these very realities relate to families and their experience of prostate cancer screening decisions. For example, an important question could be about how does West Indian American families' cultural heritage or meaning making experiences affect their PcA screening behaviors and experiences. Symbolic interactionists are also concerned about

the ways in which family members communicate intimacy and about what significance family members attach to intimate interactions. This concern is very likely an appropriate concept that could be an appropriate frame for questions for families dealing with prostate cancer screening decisions.

The conceptual interactions between the ‘I’, ‘Me’ the “self” and “meaning” the ongoing conversations that connect them form a thread that links the some key ideas of symbolic interactionism. These important ideas are sometimes referred to as “premises” of symbolic interactionism (Blummer, 1969). First, there is the idea that “human beings act towards things on the basis of the meanings that the things have for them.” Second, “the meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows.” Third, “...these meanings are handled in and modified through, an interpretive process used by the person in dealing with the things he encounters” (Blumer, 1969, p. 2). In summary these premises purport that human actions in relationship to things such as ideas, information, possibilities of illness, and health behaviors, are generally prompted by the meanings that humans attribute to the things. Meaning for human beings are constantly generated from their ongoing interactions with fellow human beings and these interactions occur within their cultural, societal, and local settings. Finally, generated meaning mutate through the user’s alteration and interpretation as the user adjusts his/her relationship to the things with which s/he deals. I see these ideas as likely related to the experience of prostate cancer screening decision making. It can be about the meaning attributed to experiences and ideas about health and screening that will be appropriate here.



LaRossa and Reitzes (1993) articulated the important themes and associated assumptions of symbolic interactionism which, when taken together aptly clarify symbolic interactions broader conceptual framework. *The first theme addresses the importance of meaning to human behavior.* Symbolic interactionism suggests that people's subjective interpretation of an object, situation, or concept operate in mediating one's role in connecting one's exposure to a stimulus and one's reaction to the stimulus. Applying this assumption to attitudes towards prostate cancer screening, prostate cancer screening behaviors, and conceptualizations of screening behaviors, marital relationships, attitudes towards screening behaviors – or the meaning it contains for them - should exert some influence on attitudes and behaviors of individuals in dyadic relationships and the subsequent success in dealing with screening behaviors in marital relationships. For example, individuals who think of screening behaviors as a necessary practice for early detection of prostate cancer, early intervention for prostate cancer, and for management of health for the self or the marital relationship may work harder at engaging in the practice of prostate cancer screening behaviors.

There are four concepts that emerge within symbolic interactionists' theories that appear to have specific applications within the framework of symbolic interactionism; they are identities, roles, interactions, and contexts. The four terms seem to have applications at all levels of the family and its systems; from the micro -level through the meso level right on up to the more macro-level in their application.

### **Identities**

“Identities” refer to the meanings attributed to the self in a specific role. For

example, within the role of spouse individuals construct their identities of husbands and wives in distinct and unique ways. One woman may see herself as a spouse in terms of being a financial provider while another may see herself as a meaningful supporter who stays at home providing significant help for the family. The concept of identities is explained well when its “salience” is considered. Salience refers to the probability that an identity is evoked or accessed within certain situations. The greater the prominence of an identity the higher motivated an individual is to perform and excel in the role-related behaviors suggested by the identity. Individuals’ motivation for actions is based on their self-conceptions are enhanced by both their identities and salience (LaRossa & Reitzes, 1993).

Salience, the thing that prompts or activates an identity, may explain why family members assume particular roles in families. For example it may explain why mothers provide more face-to-face custodial care for their children, provide more psychological care for their children than fathers, and carry out more physical and psychic tasks in households than fathers. Salience in identities is affected by a person’s “commitment.” Commitment refers to the cost of giving up a particular dimension of an identity – a social relationship, a particular type of action, or a particular performance with a family relationship. Commitment refers to the value attributed to a particular aspect of family duty; parenthood, motherhood, fatherhood. It is consistently argued that the more salient the particular familial role is to a spouse the more frequent that role will be evoked by that family member.

Symbolic interactionists also focus on the concept of self-esteem; how one evaluates oneself. The desire to maintain high self-esteem is considered a powerful

motivation for behaviors also behaviors have a powerful impact on self-esteem according to symbolic interactionists; there is a dynamic interaction between self-esteem and positive behaviors. Self-esteem is also asserted to affect conformity, interpersonal attraction, moral behavior, academic achievement, educational orientations, and various aspects of personality and mental health. On the other hand, self-derogation is implicated in physical indicators of anxiety, depressive affect, and the need for psychiatric assistance (LaRossa & Reitzes, 1993). It is plausible to think that targeting persons for the cultivation of self-esteem can be helpful in cultivating helpful screening behaviors and thus contributing to a more positive experience of screening behaviors and PcA screening decision making among heterosexual West Indian American men and their partners.

## **Roles**

Roles are “shared norms applied to the occupants of social positions.” Roles are systems of meaning attributed to particular positions that allow their occupants and other individuals with whom they interact to anticipate future behaviors and to maintain consistency in their social interactions; there are roles expected of parents, spouses, grandparents within familial relationships.

Roles assume certain levels of knowledge, ability, and motivation, and expectations about the direction, duration, feelings, and emotions associated with the roles. This suggests that there are certain norms associated with spousal, parental, and familial roles. These norms are activated in routine familial context and in extraordinary contexts such as when family members are confronted with catastrophic or chronic illness. The important questions which symbolic interactionists will ask in certain

instances may include: 1) what do people know about the illness diagnosed in a family member/family? How skillful should the family member be in performing a spousal role? 3) How motivated should the family member be about playing a caregiver or support role? 4) What is the extent, direction, and duration of the emotional work that people should do to the assumed or chosen role in the relationship? (LaRossa & Reitzes, 1993; Sandstrom, Martin, and Fine, (2001).

Roles are often better understood in the context of complementary or counter-roles. For example, the role of the husband is better understood in relationship to the role of the wife. The role of the father is understood in the context of the role of mother or the role of the child. The necessary caution here is that people often play roles in which there is not necessarily a counter-role. There can be variability in roles resulting from the social relationships and roles can also vary over time. But there are instances when roles are played with no counter roles within a relationship. For example, a caregiver in a dyadic relationship may simply be serving in the role of a caregiver with not role counterpart. In instances of chronic or catastrophic illness the person playing this role would likely be experiencing feelings, stress, and excess caregiving behaviors that may contribute negativity in her overall experience. The idea that there is a possibility of going through this experience may help generate meaning that can assist in better understanding the need for prostate cancer screening decisions.

### **Interactions**

Interactions refer to the very practical concept of social interaction that enables people to create the meaning of self, others, and situations. It is a very collaborative

process that results from the mutual awareness of self perceptions and self-presentations that result in a constant drama of interactions. Interactions take into account actions, responses, and subjective meanings of others participating in the interactive process. For example status, power and authority of the people participating in the interaction have variable impact on the interactions. As noted already there are particular meanings attributed to the self and others, but similarly meanings are attributed to situations. A situation refers to a particular interactive setting and encourages or demands a set of actions appropriate for that setting. A person may conceptualize a setting to be safe, unsafe, threatening, fair, or unfair; what matters is that the person defines or perceives the situation to be influences his/her actions (LaRossa & Reitzes, 1993; Charon, 2009; Sandstrom, Martin, and Fine, 2001).

### **Contexts**

Within the framework of symbolic interactionism the dynamic relationship between culture and behavior is emphasized. While it is asserted that culture affects individual behavior and individual behavior helps in the development of culture there is little rigidity on either extreme of this continuum. Rather, it is suggested that there is allowance for determinacy and indeterminacy within this theoretical framework allowing for the impact of culture on behaviors and vice versa. The important connection between the individual and society in modern symbolic interactionism theory is the fact that there is “a negotiated order approach” (Strauss, 1978). There are three concepts that form the basis of this negotiated order approach: negotiation, negotiation context, and structural context (LaRossa & Reitzes, 1993; Jeon, 2004; Sandstrom, Martin, & Fine, 2001 ).

Negotiation refers to the manner in which many things are achieved by such activities as bargaining, compromising and engaging in collusion. Negotiation context refers to situations in which one party in a relationship condition has information relevant to negotiation or decision making and the other party lacks the information. This negotiation context differs from one in which both parties have the information. Structural context refers to a dramatic change in a dyadic relationship situation in which one or both parties in the relationship assume new vocational or professional duties. Structural context may also refer to a change in dyadic relationship in which catastrophic illness or care giving responsibilities have to begin or change as a result of catastrophic illness upon one member of the family (LaRossa & Reitzes, 1993).

### **Meaning and Symbolic Interactionism**

Meaning is an integral concept of symbolic interactionism and in context of the present study the meaning of marriage and dyadic relationships, the meaning of experience, the meaning of illness (prostate cancer), the meaning of illness prevention/related behaviors (screening), and the meaning of decision making or prompt decision making about health behaviors can affect the functioning of the marital relationships, screening behaviors, and post-diagnosis behaviors within the dyadic relationship. Hall (2006) observed that meaning includes psychological thought and contended that “humans innately seek out meanings in things; to make sense of their world” (Hall, 2006, p. 1439). Meaning, by definition, connotes symbolism and intention (Klinger, 1998) and meaning can be understood as “shared mental representations of

possible relationships among things, events, and relationships. Thus, meaning connects things” (Baumeister, 1991, p. 15).

‘Meaning,’ for the symbolic interactionists, is a major factor in understanding human behavior, human interactions, and social processes. “Meaning is a social product made possible through social interaction with others” (Jeon, 2004, p. 251) is the gist of SI’s concept of meaning. Every human being is a meaning making person. Their assertion is that to arrive at a full comprehension of a social process an investigator needs to grasp the meanings that are experienced by the participants within a particular context (Jeon, 2004). The symbolic interactionists’ emphasis is on the lived experience of the individuals investigated – the inner world of human behavior. Their emphasis is to fully detect the perceived meaning of participants specifically their understanding of a situation from the participating individual’s point of view. Meaning, therefore, is to be grasped with a particular participant’s context and the context must accommodate the unique situation within which an investigated experience occurs (Jeon, 2004; Charon, 2009).

There is also an important relationship between meaning and behavioral goals. People typically learn meaning through “anticipatory socialization” (Hall, 2006). The concept of “anticipatory socialization” pertains to the reality that before entering into roles, situations, and contexts people learn in advance about how to behave and integrate the learning into their identity and are prepared to act or react in specific ways. The individual family and wider society in which one is raised and develops is a major source of information about one’s roles and expected behaviors when confronting situations. There are social/cultural sources of meanings and interpersonal sources of meanings

about institutions in general and more specifically about the institution of marriage (Nock, 1998; Blumer, 1969). Hall (2006) posited that for humans, things become important if they are integrated cognitively into the goals and purpose of humans. Consequently the mind attends to, process, and retain information relevant to desired goals. Hence, information relevant to prostate cancer screening behaviors, marital functioning of diagnosed individuals/families would influence what a person thinks, believes, and does about screening behaviors.

A symbolic interactionist perspective on the meaning of marriage, specifically the social meaning of marriage, is useful as this study is contemplated. Hall (2006) observed that from multiple sources of information (national pools, policies, and religious doctrines) several aspects of shared ideals of marriage are generated from within American culture and the ideas are as follows. First, there is voluntariness in marriage because people enter marriages voluntarily. Second, marriage requires maturity because there is the idea that people must reach an age of maturity before entering into marriage. Third, there is heterosexuality attached to marriage because heterosexuality is the accepted norm attached to marriage. Fourth, there is the notion of gender leadership in marriage because it is accepted that the husband is the head of the family. Fifth, monogamy is seen as the accepted ideal of marriage. Sixth, parenthood is seen as a part of marriage. And Seventh, there are specific gender roles associated with marital relationships (Hall, 2006). Marital meaning is also derived from other expected functions of marriage; personal fulfillment, expression of love, and the experience of companionship (Wyatt, 1999; Coontz, 2000). The idea of relational permanence



particularly distinguishes the meaning of marriage compared to other romantic relationship (Waite & Gallagher, 2000).

From a symbolic interactionist perspective there are also interpersonal influences on meaning and they are also pertinent within the perspective of this study. The institution of marriage, the meaning of illness, and the meaning of relationships of individuals confronted with catastrophic or chronic illness remain important as one addresses the understanding the experience of prostate cancer screening decisions in heterosexual West Indian American men and their partners. Symbolic interactionism theorizes that people are socialized by their social interaction with people within their immediate family context and within their larger social environment to think and create meaning about circumstances and concepts (Blumer, 1969; Hall, 2006). Early childhood family interactions, experiences within one's immediate family, intimate experiences such as dating and courtship, premarital sexual experiences, and other forms of premarital relationships all contribute to the notion that people form and maintain meaning about marriage together with the attitudes people bring into marriage. The interpersonal interactions may affect the cognitive, affective, and/or behavioral patterns that influence how marriage itself is experienced (Hall, 2006). The interpersonal experiences are also applicable to relationships with illness and one's notions of prevention, intervention and/or management of health while in a relationship.

### **The Concept of the “Self” in Symbolic Interactionism**

The concept of the ‘self’ is important within the framework of symbolic interactionism. James, Cooley, and Mead were the main contributors to the concept of the

self and they saw the self as an adjustment process reflecting the person and society (Schneider, 2011). It is probably important to observe what the self is not in order to better understand what it distinctively is. The meaning of the self is different from the meaning of Freud's "ego." It does not mean the "real person." It does not mean "the productive person" or "the total person". It is not the same as personality, or identity, or the actor. The symbolic interactionist proposes that "the self is an object of the actor's own action" (Charon, 2009, p. 71). The self does not act but the actor acts towards the self as it acts towards other things within the actor's environment. The self is a part of the actor's environment towards which the actor acts. The self is developed out of the social experience and the individual experiences herself/himself out of the experience and standpoint of other individuals. The self is socially created and becomes "the internal environment towards which an actor sees and acts" (Charon, 2009, p. 72). Mead's fundamental assertion about the self is that it operates as an entity that functions in constant interaction with the social world. The person and the world are not to be understood in isolation because the very development of the self is a continuous process of humans interacting with other humans. Symbolic interactionist approaches propose that the "self" develops and changes as people see themselves through the eyes of others. Thinking metaphorically, others' evaluations function as a mirror in which one sees oneself. In this regard, *reflected appraisals* refer to perceptions of others' evaluations, and *looking-glass self* refers to the idea that people see themselves through (their perceptions of the eyes of others (Mead, 1934; Jussin, Suffin, Brown, Ley, & Kohlhepp, 1992).

The “self” therefore, is a product of human interaction and there is a continuous development and refinement of the ‘self’ through ongoing process of participation in society. Mead clarifies the understanding of the ‘self’ by insisting that it is constituted of the subjective “I” a natural spontaneous entity that is unaffected by others and the objective “me” that sees self as a reflection of the what others see and what the individual sees when looking back at one’s own self. In this regard the subjective “I” and the objective “me” are in constant communication (inner conversations) before acting or behaving. The self-reflecting capacity and the capacity to internally account for the reflections of others is utilized to create meaning of the self and this results in the generation of the “social self.” When the “I” and the “me” are congruent there is conformity but if there is divergence between the two there are two character possibilities. There is either abnormal characters unwilling or unable to perform cooperative behaviors or that divergence between the “I” and the “me” can be indicative of genius in which case a person is able to be an example to the self and others (Schneider, 2011).

This idea of the self as a socially construed entity is important in a study that seeks to understand experiences and decisions within relationships. The concept of the self is typically intended to refer to naming and interpretation that one has of his or her individuality based on the role a person assumes based on the multiple applied designations one receives from others within his/her social sphere. It is a reflectively conceptualized designation that one assumes (Leeds-Hurwitz, 2006; LaRossa & Reitzes, 1993). These concepts of the “self” and “social self” become relevant in exploring how participants interpret their behaviors, attitudes, decision making processes, roles in

relationships within the context of their relationships, interactions with each other and in context of the wider society.

Mead, more precisely, saw the self as the character or personality of a person and the character experiences new information added over time. The new information results in disintegration and re-organization of character. The reflective self develops as the self is acted upon by the person in a form of self-analysis. As a person does the self-analysis there is an interaction of the self with other selves and a new self emerges. Over time the growth of the self occurs from partial disintegration, reflection, consideration of various influences, and re-emergence of the self. This process of self-development is termed moral development. Failure to adjust in self-reflective growth is “selfishness” and is immoral according to Meade (Schneider, 2011).

### **Symbolic Interactionism and the Present Study**

The contribution of symbolic interactionism to the present study is the initial understanding that ultimately people are socially created and that they can create new societies at a micro and macro level in which to live. Families were defined early as a “unity of interacting personalities” (Burgess, 1926) and the families of the participants of the studied group, West Indian American men, are themselves unified groups of interacting personalities. The immediate concern then is to discover the result of their attributed meaning, their self-concepts, their identities, their roles, their interactions, and their contexts. Also, through an integrative approach determine and better understand the experience of prostate cancer screening decisions among heterosexual West Indian American males and their partners.

West Indian American men with their cultural, ethnic, and, racial realities may have, over time, engaged in social interactions and in the process have developed meanings for the various phenomena in their lives. Within the theoretical framework of symbolic interactionism the meanings that they attribute to illness, health maintenance, attitudes towards prostate cancer, prostate cancer screening behaviors, prostate cancer screening decisions, and the experience of their screening decisions are to be understood through their interactions. Their interactions within their cultural, social, familial contexts contribute to their concepts of their selves. Their attributed meanings of their selves is a constantly dynamically developing concept influenced by their own individual view of themselves and the set of reflections received from others in their society. The constant mental/internal conversations of individuals within the community have impact on their experience, decisions, and actions regarding prostate cancer screening behaviors.

Following the themes of symbolic interactionism it is also plausible to think that interactions at family level and within their culturally and ethnically unique communities may result in the cultivation of specific meanings within this population. They might have nurtured distinctive identities within their families and/or dyadic relationships and perform roles that are exclusive and important within their relationships. Their interactions over time within their particular cultural context could have resulted in particular patterns of thinking, decision making and behaving that contribute to unique experience in prostate cancer screening decisions. For example the health care role within the family may be the domain of the female (spouse/partner) in a relationship and that role in ensuring health care for the family may routinely exclude the male because over time the cultural norm may have dictated that that is what it should be. This role may

need to assume new meaning and become expanded to help in enhancing or changing the experience of prostate cancer screening decision making experience within the family.

While cancer has a discouraging effect on the diagnosed person it also has a devastating impact on other relatives – parents, spouses, children, and of the in general has a devastating impact on marriages. Issues affecting families with cancer include coping, economic, sexuality, and fertility issues. Marriages and committed relationships are also affected by cancer in unique ways because the relationships are strained by the illness and survival is related to marriage and the marital quality. Married cancer patients have higher survival rates than their unmarried counterparts. People who were going through a divorce when they were diagnosed with cancer had the lowest survival rates among PcA diagnosed persons (Clay, 2010)

### **Justification of Use of Symbolic Interaction Theory**

The reasons for the justification of utilizing the symbolic interactionist theoretical approach may be due to some practical reasons. First, symbolic interactionism is useful in the study of every-day social interactions because some of the most important interactions of human beings occur in face-to-face interactions (Leeds-Hurwitz, 2006) and symbolic interactionism suggests and assumes a particular methodology; gathering of data through the observation of people in real life settings. Blumer (1969) supports this methodological approach by observing that symbolic interactionism assumes:

“Its empirical world is the natural world of such group life and conduct. It lodges its problems in this natural world, conducts its studies in it, and derives interpretations from such naturalistic studies. If it wishes to study religious cult behavior it will go to actual religious cults and observe them carefully as they carry on their lives...its methodological stance, accordingly, is that of direct examination of the empirical social world” (Blumer, 1969, p. 47).

This suggests that symbolic interactionism is an appropriate theoretical perspective that can guide a qualitative methodology, question formation and interviewing strategies to examine the experience of prostate cancer screening decision strategies of heterosexual West Indian American and African American men and their partners.

Second, because the model has a non-normative approach to its evaluation of families and in the therapeutic interventions it has the potential to offer an elucidating understanding of meanings, interactions, cultural realities, and the utility of evolving meanings diagnosed individuals and partners experience. SI's applicability seems very relevant to the present research in that it offers a way of thinking about experiences of West Indian American men and their partners in a unique decision making situation. West Indian American men/families under stress about the possibility of being diagnosed with prostate cancer or as they interact with therapists or health care providers seeking to develop proposals to encourage screening or early intervention may be helped by a framework of SI guiding understanding and flexible thinking in the service that they provide.

Third, there seems to be relevance of the essential concepts of SI in conceptualizing the experience of prostate cancer screening decision making that brings with it the task of enabling the family to deal with other possible family challenges rooted in their family interactions. Such issues as their identities, roles, interactions, meaning, and concepts of the self, seem relevant to the understanding of the overall meaning generated in the community. Hence appropriate questions can be generated with this theoretical perspective guiding the researcher's thinking. The choice of utilizing symbolic

interactionism allows the researcher to take advantage of concepts of meanings, identities, roles, and the self and deal very deliberately with the illness manifestation. The framework offers great opportunity to explore with family their historic manner of attributing meaning to illness or traumatic events. The framework is accommodating to their unique cultural and ethnic background.

Fourth, the applicability of meaning, self, identity, roles, and contexts in addressing the concepts related to experience of prostate cancer decision making among heterosexual Caribbean American men and their partners seem appropriate. The appropriateness results from the fact that their unique cultural factors and values may generate psychological factors such as values, beliefs, intentions and motivations that prompt helpful or harmful behaviors particularly in relation to prostate cancer screening decisions and behaviors. The key concepts that the symbolic interaction framework espouses seem relevant and essential to this study. The theoretical framework allows for an outlook on family issues that will be appropriate for this research and can generate questions that probe the groups in the right manner to generate knowledge.

Fifth, the symbolic interactionism theoretical framework /model allows for sensitivity to cultural, ethnic, and gender issues that may be very relevant to this population. The framework can deliberately and intentionally accommodate and recognizes issues pertaining to migration, ethnicity and race. The deliberateness can be accomplished as it remains attentive to the represented group's experiences in their interactions, unique meaning making, meaning evolution, and responses to "things" in their cultural settings. The concepts of SI are all relevant concepts that cultural considerations will bring to prominence as this population of some recent and not so



recent immigrants are considered in the research. Masculinity, gender and power issues will likely be prominent in this population and as families are served the framework allows for deliberate work that seeks to clarify and process issues related to these concepts.

Finally, the symbolic interactionist's theoretical framework allows for a non-judgmental approach that will be very relevant for this population in their cultural context. In doing investigative work about meanings etc., process work, or endeavoring to understand identities and concepts of the self, important empowering experiences can be realized in the target group. The experience of empowerment can also be accompanied by the experience of feeling respected by the studied population. This SI framework, therefore, allows for a non-judgmental approach in questions and questioning that offers empowerment, respect, and safety for the persons and families being served by the researcher and therapist. These elements in the approach will likely enhance cooperation and success in research and service to this population.

## **CHAPTER FIVE**

### **STUDY METHODS AND DESIGN**

The study employed an exploratory focus group qualitative research design. Specifically, focus groups were conducted with individuals and couples who met the inclusion criteria for this study. In the fields of mental health and family sciences the research methods utilized are most often quantitative in orientation. For example, researchers typically use a deductive approach and hypothesis testing with set quantitative outcome measures that allow for statistical testing or prediction. The results from such research are often general laws or principles with predictive power (Searight & Young, 1994). The usefulness of such research methods can be observed in the high impact of study results in a number of different areas such as family policy and the appropriateness of different treatment modalities. On the other hand, qualitative inquiries are typically inductive, with a focus on description, understanding and explanation of the context of people's lives rather than prediction. Thus qualitative inquiry was more concerned with hypothesis generation than hypothesis testing which is characteristic of quantitative methodology. This approach fits within the framework of the goals of this study of seeking to understand the meaning of the experience of prostate cancer screening decisions among heterosexual West Indian American men and their partners.

The value of qualitative research methods is most critical in instances when there are attempts to understand complex naturally occurring phenomena that are not easily amenable to experimental control. Its utility is heightened when the goal of the research is to understand subjective experiences or in cases where researchers are attempting to conduct an initial inquiry that has been previously un-researched (Searight & Young 1994). For instance, the complexity of family systems and the issue of family

functioning in light of the threat of prostate cancer and prostate cancer screening decision making rendered the issues appropriate for qualitative research. The empirical literature that addresses the impact or threat of prostate cancer among African American and West Indian American men and their partners is still in its nascent stage. The personal issues associated with prostate cancer coupled with the challenges that men usually face in speaking in-depth about illnesses strongly suggest that a qualitative research approach would be particularly useful.

Qualitative research has a documented history dating back to the Greek Historian Herodotus and continued through anthropological and sociological studies through the works of many renowned scholars. Examples of prominent individuals using qualitative research for their inquiry include individuals such as Darwin, early British anthropologists, Bronislaw Malinowski who is often regarded as the founder of ethnography, and The Chicago School's Robert Park inquiry that was based on direct participation with "deviant" urban subcultures. Others such as Gregory Bateson, and David Rosenhan's whose work with schizophrenic families and within psychiatric institutions respectively (Searight & Young, 1994) provided groundbreaking insights into psychiatric practice. In recent decades work was being done utilizing qualitative research methods for family therapy, family studies, and family medicine (Daly, 2007; Searight & Young, 1994). Utilizing qualitative methods of research in the field of family therapy is proving successful because the method "has been described as more philosophically compatible with family systems theory than are linear, quantitative models" (Searight & Young, 1994, p. 118,). The compatibility is also demonstrated by the emphasis of qualitative methods on social contexts, multiple perspectives, and the eagerness to

describe patterns rather than resorting to reductionism of phenomena. Furthermore, qualitative methods are also effective in forming a link between research and the clinical practice of family therapy.

There are multiple data gathering methods that may be utilized in the conduct of qualitative research. The data gathering methods include participant observation, various types of interviews, text and documents/procedures analyses, and focus groups. The data collection approach selected for this research was focus groups.

### **Focus Groups**

Focus groups have a history as a pragmatic research tool that is used in multiple disciplines. As noted earlier, focus groups consisted of 6 to 10 members who typically meet for 1 ½ to 2 hours and was facilitated by a trained investigator/moderator. The facilitator was flexible in that the conduct of the focus groups ranged from relatively little direct control to a more directive approach to the content and structure of the group (Morgan, 1989; Daley, 2007). For example, in this study, the researcher used some direct control by following a set of questions and sought to get participants to respond to the issues identified by the interviewed protocol and the participants. In working with the focus groups, the investigator led the group through the specific questions and probes listed in the protocol (see Appendix). The focus groups were a pragmatic approach that allowed the researcher to understand issues of interest from a social group perspective and afforded the facilitator opportunity to probe and to direct the discussion of the group in order to generate a better understanding of the meaning they attributed to the issues related to prostate cancer.

There were no rigid conventions about the number of focus groups that were necessary for conducting this qualitative study. More importantly the issues were explored until saturation to the point of detecting the recurrence of particular themes and issues was reached. However, theoretical sampling was carefully employed to assure triangulation by type of persons relevant to an issue (Daley, 2007). Consequently, the researcher attempted to sufficiently detail the issues by conducting six focus groups.

### *Exploratory and Experiential Tasks of Focus Groups*

While focus groups can serve multiple purposes, the focus of this dissertation allowed for attention to the interactions among West Indian American and African American men and their partners around issues of prostate cancer. The primary tasks addressed in the use of focus groups here were exploratory tasks and experiential tasks (Fern, 2001). The exploratory tasks were related to the creation of the ideas through the collection of the unique thoughts of the groups' participants as they talked about their experiences with prostate cancer screening decision making. Specifically, focus groups enabled researchers to identify participant's needs at the individual and couple levels exploring their expectations related to prostate cancer screening, and looking for any additional and unique information they present. Experiential tasks refer to the observations of the attitudes or the learned behaviors that the participants take for granted in their lives. It includes their shared experiences, their preferences, intentions and behaviors. Their overall responses based on the meaning they have generated over time. The focus groups were utilized to generate a better understanding of what Fern (2001) referred to as the "natural attitudes" (p. 7) of the participants. The groups allowed this

researchers to immerse himself in the perspectives of the issues, in this instance the family related issues that may have affected the experience of prostate cancer screening decisions and responses or potential responses to prostate cancer diagnosis. A logical concomitant to the sensitizing and immersion in perspectives of the participants was that focus groups also afforded the researcher guidance for decision making about the next steps in a particular research; including what issues to probe farther, who next needs to be interviewed, and the broader research strategy that needs to be embarked upon. The research was not utilized to generate theory.

The focus groups approach was used as a stand-alone method to provide data about the experience of prostate cancer screening decision making among heterosexual West Indian American Men and African American men their partners. In a broader context the focus groups brought attention to the wider threat of prostate cancer and its impact on families of West Indian American and African American men. The focus groups offered the opportunity to observe the interactions between these families and the way they talked about specific aspects of their family functioning in relation to the experience and decisions related to screening for the disease. The meaning of their support strategies, coping strategies, common experiences, and unique psychological responses were almost invariably explored in focus groups.

In order to achieve the goals for focus groups the groups' membership was typically homogenous with attention given the inclusion criteria that guided the study. For example, illness characteristics such as diabetes, hypertension, or prostate cancer are possible areas of uniqueness to a particular group that may render them important to a researcher. The inclusion criteria for participation in these focus groups were West Indian

American (of African heritage), African American heritage, and heterosexual orientation, being male, being at or over 21-years-old, and the spouse or partner of the male in the focus groups. Focus groups provide the opportunity to observe the interaction of group members while discussing an issue that is of importance to the group and the researcher (Daley, 2007).

There are multiple advantages of focus groups which seemed to operate in this setting. First, there was efficiency in that in a focus group multiple individuals were interviewed in a single session. In this process the focus group allowed the opportunity to gather the testimony of the people we intend to help in Marital and Family Therapy. Second, the focus groups contributed to the illumination of understanding of issues pertaining to the experience of prostate cancer screening decision making among heterosexual West Indian American men and their partners that other forms of research have not yet fully illuminated. In this instance there is a need for additional understanding of the issue understudy and direct testimony can improve the understanding (Krueger, 1994).

Third, focus groups provided the benefit of generating information when the area of study is very specific. In this instance a focus group was very useful in eliciting information about the experience of prostate cancer screening decision making of families in which the men were at risk for prostate cancer diagnoses (Searight & Young, 1994). Fourth, the results of the focus groups will be used to guide the development of questions and areas that will be explored by using in-depth interviews with individuals who meet the inclusion criteria. Fifth, these focus groups had the advantage of providing

data that will allow the researcher to find and pursue unanticipated issues in any research (Kruger, 1994).

Finally, there may have been disadvantages associated with the use of focus groups. For example, focus groups had relatively small sample sizes and their results could have been biased. Also, largely because in the process of utilizing focus groups individual may have had unique and unusual opportunities to express their views and feelings on issues of interest to them. Intense emotions of anger, joy, and distress about a particular topic may have engendered excessive venting of feelings about a topic. Therefore, caution was taken when focus groups are utilized to account for these possibilities of bias (Castellblanch & Abrahamson, 2003).

To address these challenges, the researcher attempted to maintain the size of focus groups at no less than six participants per session. This seemed to be a reasonable approach to achieving appropriate focus group outcomes pertaining to group size per session. In order to address the possibility of excessive venting the researcher/moderator attempted to orient participants at the beginning of focus group sessions by observing to participants that researcher would attempt to keep participants on topic and will gently attempt to keep group focused on topic under discussion and relevant to the focus group. Researcher also indicated to participants that there was a need for all participants to participate in discussions and that attempts would be made to move discussion along in order for all participants to get an opportunity to offer their comments and thoughts on ideas discussed. During sessions researcher/moderator redirected participants to the issues being discussed when/if participants moved away from or attempted to veer off topic. To address the issue of bias researcher/moderator often asked participants if there



were alternative views on a topic being discussed in instances when ideas seemed to be trending in one particular direction.

### ***Participants and Sampling***

The participants in the focus groups were individuals who shared a common cultural heritage and have a specialized knowledge of a shared experience as African Americans and West Indian Americans respectively. For example, there were individuals of West Indian descent who probably had a shared knowledge and common cultural experience of prostate cancer screening decision making among heterosexual West Indian American men and their partners. On the other hand, they were African Americans who also had a shared knowledge and common cultural experience in that they are individuals who probably had knowledge of the experience of prostate cancer screening decision making among heterosexual African American men and their partners. In this context, we sought to better understand how this issue affected the men's families (spouses or significant others). In order to understand an issue, qualitative research often seeks triangulation versus large numbers. Triangulation is the attempt to look at an issue from a variety of perspectives that may be relevant to best understand the experience of prostate cancer screening decision making among heterosexual males and their partners within the population under discussion.

The procedure employed here is purposive convenience sampling. The participants were identified and recruited based on specific and/or unique shared experiences and characteristics (Daley, 2007). More specifically, African American and West Indian American men of various age groups were selected for their respective focus

groups. Similarly, couples representing different age groups from African American and West Indian heritage were selected for the focus groups.

As noted earlier, participants were selected using convenience sampling to fill the inclusion criteria for each of the different type of focus groups. This approach was intended to foster better understanding of the experiences and fears around prostate cancer for African American men. Consideration was given to the issue of diversity within the African American population. As such, participants were drawn from the population centers of New York City and the surrounding Boroughs of Brooklyn and Queens because these areas represent census blocks, which contain large numbers of West Indian Americans. They were also drawn from population centers of San Diego, Los Angeles and the Inland Empire in the State of California. This was intended to include a number of African American men in the focus groups.

### *Ethical Considerations*

While focus group research precludes anonymity participants in this study were granted assurance of confidentiality. Before the research was conducted, the research proposal was reviewed by the Loma Linda University's Institutional Review Board (IRB) to ensure that the overall research proposal was consistent with the University's ethical standards of research. After details about the research were presented to participants and discussed in the form of explanation of study (see Appendix C), the informed consent form (see Appendix D) was then given to participants, reviewed with participants and they were given opportunity to sign the consent forms. After consent forms were signed by participants they were then offered the demographic questionnaire (see Appendix A)

fill out. All identifying information pertaining to the participants were be systematically changed so that pseudonyms were be used when presenting data and extreme care was taken to make anonymous any information that might be linked to the participants. Third, to ensure confidentiality of participants' tapes of the groups will be destroyed as soon as quality control measures to assure accurate transcription of information are taken. Special strategies were used to secure participants and research data in a manner that allows identifying markers such as names and other identifiers to be separated from the data. Transcribed research data were stored in locked file cabinets separate from signed consents. File cabinets will be stored in secured locations with access allowed only to IRB certified researchers. Finally, all researchers signed statements of confidentiality that guarantees the researcher's commitment to protect the data and maintain participants' confidentiality.

### ***Recruitment and Scheduling of Participants for Focus Groups***

Participants for the study were recruited via placing flyers in doctors' offices, treatment centers, community centers and churches as well as through community talks (at community and/or church meetings) about prostate cancer issues, and at **Changing Health for Adult Men with New and Great Experiences (PROJECT C.H.A.N.G. E )** health fairs held in Riverside California and in Brooklyn New York. The individuals who fit the characteristics required for the types of focus group planned were identified and then asked to participate in a focus group. Potential participants were provided a complete explanation of the purpose of the research and the procedures involved. The inclusion criteria for the focus groups were: 1) heterosexuals of African American

descent or West Indian American of African descent, 2) adult men 21-years-old and above, and 3) spouses or significant others of adult men 21-years-old and older living with the men in committed relationships. The inclusion criteria were clearly defined and explained to individuals interested in participating. The focus groups were conducted with participants in the following order: first, African American men only, second, African American men and their spouses, third, West Indian American men only, and finally, West Indian American men and their spouses. Since focus groups require a relatively large number of persons to be at the same space at the same time, they are notorious for “no shows.” Therefore, over-recruiting was done by a factor of 50%, recruiting 15 persons to reach the target 10 per group (Daley, 2007; Wilkinson, 2004).

Once participants were recruited, reminder phone calls (choice of recruited individual) were made and individuals were invited to a safe, community friendly site for individual focus group sessions at times that were convenient to participants. Scheduling for the groups was done with much advance planning in order to give participants proper planning times and easier ability to place sessions on their calendars. Participants were asked for 2 hours of their time: a half hour for the welcome and consent procedure, and one and one half hour for the conducting of the actual focus group (Daley, 2007).

A total of 46 individuals ultimately became the focus groups members. The groups were formulated as focus groups of African American men only, African American couples only, West Indian American men only, and West Indian American couples only. The groups were conducted in the counties of San Diego and San Bernardino in California and from Kings County New York. The focus groups were conducted by a single facilitator doing this work as part of a wider research team that is

looking at issues related to prostate cancer and the African American men and their families. **Table 1** describes the demographics of the participants in each of the focus groups. For the men only African American groups there were 2 focus groups with a total of 14 participants. The first group had 6 participants and the second group had 8 participants (both in San Diego). For the men only West Indian American groups there were 2 groups and a total of 10 men with 5 men in each group one in San Bernardino and one in New York). For couples only groups there was one African American only couples group with 8 couples and 2 West Indian American couples groups with 4 couples in one (the San Bernardino group and 8 couples in another (the New York Group).

Notes were taken and overall themes were then acquired utilizing a focus group approach to qualitative analysis (Strauss & Corbin, 1998). Open Coding yielded numerous discrete themes suggesting that saturation was reached after six focus groups. “Discrete” is here defined as a single idea or concept typically framed as a self-contained sentence or phrase. As open coding proceeded new responses were compared with previous responses to determine similarities and differences in meaning. The nine themes were then sorted out by further coding and categorized into common constructs that represent the principal ingredients in the experience of prostate cancer screening decision making process among heterosexual African American and West Indian American men and their partners utilizing both exploratory and experiential information gathering approaches from the focus groups (Fern, 2001). Clinical applications were unveiled during the process in that motives were unveiled, resistance to screening decision making were exposed, and predispositions, biases, and prejudices regarding screening decision making were uncovered.

In the experiential information the thoughts, feelings, and behaviors shared by the members of a particular cultural community, race/ethnic group, community or family unit are generated and analyzed. The task was to deal with and determine the information and meaning known to the individuals within the group; knowledge and meaning known and shared by one or multiple group members. Additionally there was attempt to bring to the surface information that may have been suppressed by some individuals within the group but unknown to others. The task of the moderator was to make this information public within the group (Fern, 2001). The exploratory tasks were also done through attempts to discover the new ideas, unique thoughts, and discovering the unique thoughts, identifying the needs, expectations, and issues related to their experiences of prostate cancer screening decision making.

After these initial steps, the researcher proceeded to axial coding (Corbin and Strauss, 2008) to examine the emerging categories for subcategories and consider their relationships to each other. Efforts were made by the researcher to address similarities and differences towards screening behaviors within the groups that were involved in the focus group discussions.

These constructs were than further reduced after reviewing for redundancy and then the remaining constructs were prioritized and organized to yield a menu of five key ingredients that seemed to represent the concepts utilized in the experience of prostate cancer screening decision making among African American and West Indian American men and their families.

### *Focus Group Questions Content and Format*

The use of focus groups in this research was conducted with the intention of determining and understanding meanings, experiences, perspectives, and conceptualizations of issues surrounding the prostate cancer screening decision making experience of heterosexual West Indian American and African American men and their partners. As mentioned earlier, focus groups are usually conducted in comfortable, friendly environments, with persons seated in a circle with chairs facing each other and the facilitator seated among them. The facilitator met with participants in the meeting space over light refreshments up to a half hour before the actual group began. This allowed the facilitator to start building rapport, allowing participants to meet each other and help them relax which was further supported by friendly, non-emotional ice breaker questions to start out the group discussion. Throughout the discussion open ended journey questions (no more than 7-10) with probes back to the group were used to get an open discourse among participants going (see Appendix B). This format was designed to encourage spontaneity and opportunities for interactive discussions. Though there are some specific journey questions most questions were phrased in order to acknowledge experiences, personal perspective, and perceptions. With this approach the researcher/facilitator encouraged participants to share their experiences in order to achieve a fuller understanding of the totality of their lived experiences. The process began with a specific engaging question to initiate the participant's response and then the researcher/moderator continued to direct and to probe to get fuller clarification of the issues being probed (Daley, 2007).

In this study the questions posed to the focus groups were to address issues and experiences such as prostate cancer screening behaviors, contextual issues, knowledge about prostate cancer, knowledge about the benefits of prostate cancer screening and the things that affect the decision to seek screening, family response, and potential effect of prostate cancer diagnosis on family functioning (understood as the level of marital satisfaction or marital discord) and issues of how culture may affect these dynamics (as masculinity, fatalism, and spirituality).

The journey questions (see Appendix B) that were designed to capitalize upon the dynamics of participants' relationships, human communication as well as the human cognitive process pertaining to the subject being researched (Krueger, 1994). The different categories of questions that were used in the focus groups were; a) opening questions, b) introductory questions, c) transition questions, d) key questions, and e) ending questions.

The opening questions were a type of questions asked in a "round robin" format allowing each person to offer answers. The opening questions are to encourage each participants a short time to offer factual answers to a non-conflict, safe question. The opener question was followed by a couple of introductory questions to introduce the general topic of discussion and offer participants opportunities to reflect on their experiences that pertain to the topic under discussion. Transition questions took the conversation to the "key focus questions" on prostate cancer and prostate cancer screening issues and help participants to comment on the wider range issues related to the topic of the study. The key questions were the questions that drove the study. They were the questions that required the greatest consideration in the study analysis. When the key



questions were exhausted, the discussion ended with an empowering question that allowed each participant to regain their composure as they likely shared some personal information during the focus group. These empowering ending questions were utilized to bring closure to the discussion enabling participants to be reflective on their previous comments and allowing them to look ahead toward solutions (Krueger, 1994; 2002).

### *Validity of the Study*

This study was conducted from an objectivist epistemology which assumes that there is a reality that exists outside of one's personal thought patterns. It was the task of the investigator to discover the reality that exists in the experiences of the participants. In this instance there was a search for the reality that existed within the world of the persons that should have the experience of prostate cancer screening decision making related to their seeking PcA screening. The experience of these participants should also relate to their understanding of their potential for diagnosis with prostate cancer. The reality of the experience of the families of men with the potential for being diagnosed with prostate cancer as they are involved in the screening decision making was also important focus of discovery. This research was done with an understanding that there is a sustained, replicable reality that can be discovered through this accumulative scientific effort of the focus group work (Daley, 2007). From this objectivist perspective there was a pursuit of truth and in the pursuit facts are discovered in a manner that separated the knower from the known. The moderator attempted to discover the reality without influencing the reality. To achieve and maintain validity the facilitator attempted to deliberately keep personal values and biases from influencing the discovered truth. From this objectivist

perspective the question of validity focuses on the capacity of the moderator to remain neutral and rested upon the influence participants have on each other. Within the group if it was perceived that participants were being “biased” steps were taken to encourage participants to express their “own views” rather than reflecting other peoples’ views.

Related validity concerns that were addressed to enhance validity are Fern’s (2001) three threats to validity: 1) compliance, 2) identification, and 3) internalization. Compliance refers to respondents’ responses perceived by the respondent to be consistent with what the interviewer wants to hear. Identification refers to a respondent’s response that attempts to be consistent with the response of a person to whom s/he is attracted. Internalization refers to deeply ingrained opinions that are personal and less affected by influence (Fern, 2001). The interviewer/researcher attempted to use expert steps to nullify the effects of these phenomena in order to prevent the compromise of validity in the research group. These included careful training in nonjudgmental conduct of discussions and careful preparation by dissertation committee chairperson. The investigator also was encouraged to first cognitively clarify his biases so that he could have actively tried to avoid them. Beyond the initial training researcher maintained contact and discussions with the dissertation committee chairperson after every focus group session and engaged in debriefing activities during those discussions.

Because this focus group study was attempting to generate the knowledge residing in the group members it is important that the facilitator remain faithful to the principles of trustworthiness, authenticity, and credibility. In the process the attempt was made to honor the principle of “descriptive validity” (Maxwell, 1992; Walsh, 2003) by accurately reflecting the data and also attempting to allow the data to accurately tell what

the participants said and did during the research process. In the interpretive process there was also an attempt to be faithful to “interpretive validity” by seriously attempting to capture what the participants said and did during the interviews.

Because the researcher’s is a West Indian American with relatives who have been diagnosed with prostate cancer, researcher’s subjectivity could also have been a threat to the interpretive and analytical process. To protect from subjective bias and to prevent the researcher’s bias from becoming a challenge to the reliability and validity of the overall research and to protect the research findings from undue influence of researcher’s bias, during this investigation there, was a constant attempt to deliberately engage the Dissertation Committee chairperson with the specific purpose of allowing the committee chairperson to be the check on the researcher’s subjectivity. His experience and competence was sought to successfully provide countervailing effects on the researcher’s subjectivity.

### *Analytic Strategy for Focus Groups*

All focus groups were taped and transcribed verbatim to assure that important words of the participants would be accurately presented in research. Once text files were available they were systematically analyzed. There are two main dimensions of the analysis of focus groups discussions. First, the focus group’s findings are organized around a common goal for the people in a particular situation. The goal of the participants in this research was to grasp and understand the experience of prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners. As this was done the issues that appeared to be the key factors

affecting their efforts to reach this particular goal were also documented. In this study, for example all the goals (i.e. some of the things they are trying to achieve within their families as they dealt with the experience of screening decision making) were documented. There was also the attempt to record their experiences with regards to the possibility of diagnosis of the disease or the experiential realities related to the actual diagnosis of PcA in the men and their immediate families. The important emerging factors that the participants were using to help themselves achieve their familial goals were noted.

Using grounded theory approaches (Charmaz, 2010) the analyses began with first line (line by line) emergent coding. The resulting universe of codes were then organized into a final codebook organized by emerging themes and sub-themes and codes within that were defined to assure a clear understanding of the underlying concept in the codes that were captured. Once the codebook was created and defined, (DeCuir-Gunby, Marshall, & McCulloch, 2011; Moreno, Egan, & Brockman, 2011; also see MacQueen, McLellan, Kay, & Milstein, 1998) it was then applied to all transcripts. Proceeding with emergent codebook building allowed unanticipated issues to come to the surface and inform whatever thoughts may have guided the inquiry in its original aims. All subsequent analyses were conducted using constant comparison of the codes and its defined properties. This approach seemed appropriate in this qualitative study. The focus groups analysis itself does not test hypotheses; its intention is to produce understanding of the experience of prostate cancer screening decision making among the heterosexual West Indian American and African American men and their partners and generating

hypotheses in the process. To accomplish this and to closely tie results to the data, a systematic approach to data mining was utilized.

Debriefing was the most immediate aspect of the analysis after data were collected during focus group sessions. After each focus there will be immediate debriefing in which the researcher informed the participants about the goals and purposes of the study and clarified any concerns and/or anxiety of the participants in the focus groups. The debriefing also included the researcher/moderator attempts to make special notes and comments about the focus group processes and the significance of data. Participants' perception of their experience was sought and documentation of their experiences was done. Beyond this immediate debriefing there was also a debriefing between the interviewer and dissertation committee chairperson to enable reflexivity about the plethora of thoughts, information, and ideas about the research that were racing through the interviewer's mind. This aspect of the debriefing helped the researcher address the sociocultural, geographical, and historical situatedness together with personal biases and concerns brought to the research experience. The debriefing also helped provide guidance to the researcher as the research activities proceeded (Leech & Owens, 2008).

Another tool of qualitative analyses was analytical memo writing. Memos are write-ups or miniature analyses about the emergent themes/knowledge and learning perceived to be generated during the research; this was done as the research proceeded. Whatever was deemed to be the necessary length of the memo (a few sentences to a few pages) to adequately capture the concepts and patterns that were appearing to emerge from the data were documented (See Appendix VI for a more detailed memoranda

compilation). Memo writing was particularly done after focus groups with the deliberate intention of recording essential information pertaining to the recently concluded focus group session. For example, after the first focus group the researcher wrote,

Health seemed to be well conceptualized during the discussions generated during this focus group. Health seemed to be thoroughly conceptualized during the first focus group session. Health conceptualization was often stated in relationship to family mostly or drawn into relational terms that pertained to person and /or families. This seems important. Health is probably not an individualistic item in the minds of these participants.

During the review of the fourth focus group (West Indian American men only) researcher documented in memo,

Prostate cancer as a threat to manhood and sexuality was expressed as a very concerning issues for the men in the group. They expressed fear of PcA as a threat to their masculinity. It seemed to me that the fear featured as a part of the prostate cancer screening decision making experience with these men.

The memo writing followed the focus group debriefing session and relevant information about participants and responses were documented during and after the focus group sessions. This written record was also a part of the text that was coded. Responses to questions posed by the interviewer were noted and questions raised by the participants during the session were also documented in the memos. In the end, it was anticipated that the analyses would lead the researcher to a “theory” fitting the experiences of the target population.

## CHAPTER SIX

### RESULTS

A total of forty-six individuals in focus groups of African American men only, African American couples only, West Indian American men only, and West Indian American couples only groups were conducted in the county of San Diego and San Bernardino in California and in Kings County New York. There were total of four men only focus groups and a total of three couples only focus groups in which the forty-six individuals were distributed.

*Table 1 Focus Groups Participants*

<i>Focus Groups &amp; Their Composition</i>	<b>Number of Persons/Couples</b>	<b>Total Number of Participants</b>	<b>Number of Groups</b>	<b>Location of Groups</b>
Men Only African American	14	14	2	San Diego
Men Only West Indian Americans	10	10	2	San Bernardino & New York
<b>Total</b>	<b>24</b>	<b>24</b>	<b>4</b>	
Couples African Americans	8 couples	16	1	San Diego
Couples West Indian Americans	12 couples	24	2	San Bernardino & New York
<b>Total</b>	<b>29</b>	<b>30</b>	<b>3</b>	

Table 2 summarizes the key themes that emerged after the sequencing of open coding, and axial coding of the focus groups sessions were completed and reviewed. The key codes were organized into five dominant themes which were: 1) uniquely acquired

health related familial conceptualizations, 2) familial meaning generated by notions of knowledge, beliefs, and intentions, 3) settled mindset conditioning patterns of meaning of experiences, 4) meaning and motivations generated in relationships contexts, and 5) culturally rooted patterns of meaning (See Table 2). Each of these themes is explained more fully below. Their interrelationships are more fully explicated to illustrate their relationship to the experience of prostate cancer screening decision making among heterosexual West Indian and African American men and their partners.

### **Factors Contributing To Participants' Goal**

Recognizing the goal of the participants as primarily to better understand the experience of prostate cancer screening decision making among heterosexual American and African American men and their partners there were some key factors that seemed to be associated with their efforts to reach this goal.

#### ***Achieving and Maintaining Good Health***

First, focus groups discussions seemed to suggest that participants were striving to understand how to achieve and maintain good health. This seemed to be indicated by participants' expressions of what health means and their desire to achieve it. For example a sampling of comments is as presented. One West Indian American in a couples group reported "Health to very important to me. me is very important the concept of health means to me as a family. Health is wealth. It says that our body is the temple of the Holy Ghost..." This understanding and desire was further emphasized by a female spouse in the same group in these words:



I think when I think of health I think of it in the holistic point of view in addition to physical wellness it is health in all aspects. Physically, mentally... And It is the foundation without health we basically can't do anything. We need health we need to be healthy in order to function in all capacities in all aspects of life.

Health is wholeness to me is a holistic thing.

A West Indian American male in a couples group stated:

I just didn't think about it until I was hospitalized about six or seven years ago and then I was brought back to the reality until I understand that I have to take care of myself. Most of the time it was an afterthought. We now have to be aware of the reality that we have to keep the optimum health as much as optimum health as possible.

While a West Indian American woman reported that health is "well-being I think for me it is the complete state of well-being for yourself and your family. The absence of diseases maybe I should say pain, physical healthy, emotionally healthy, and spiritually healthy"

Health and the desire for good health was often spoken in aspirational terms suggesting that the participants in the focus groups were eager to achieve good health whenever and wherever it was possible.

### ***Partner Collaboration to Address Health and PcA Screening Success***

A second factor that seemed to be associated with participants attempting to achieve the goals of understanding the experience of prostate cancer screening decision making among heterosexual West Indian and African men and their partners was their

repeated emphasis on the need for men and partners to collaborate to address health and PcA Screening decision making success. One African American male in a men only group lamented about how problems in his family compromised his ability to have good health by stating:

We touched on that a little earlier ... I felt it was huge when I felt as if my family was being torn apart. I felt as if my family was taken away from me. ... I was thinking a lot of it was my fault. .. I was thinking that I am not performing to my capacity. I came out of that thinking that... I saw it as or I based a lot of what I did as what I thought was my role. ... My health also. Just as I internalized as what I should be doing and what I should have and what I should not be doing. As the expectations not being met. ... I am coming to where after a few years, we are coming to where I came through that and I am happy as a person... That definitely was a huge thing for me. It was family based.

An African American male in one group applauded the participation of his wife in his dealing with diagnosis and treatment of PcA. He advocated that men should be engaging spouses and disclosing to spouses details about the men's health by noting:

I am very comfortable talking with my wife. In fact she is at some of my appointments with me. she was there at the doctor's office with me. as we went she sat down and was able to ask questions... And as she went with me he drew the prostate and whatever else and she was able to say some of what she saw was consistent with what the doctor was saying. So that's why it is good to let your family know.

Another African noted, "my wife was very good with the children with regards to certain achievements within the family she made health a top priority..." as he lauded the need for collaboration to address general health and PcA screening issues. This thought was familial collaboration for the achieving of screening was elaborated by an African American female and an African American male respectively as she said "well it's something that I do sometimes but not all the time (accompany her husband to the doctor and insists on him going). And it is something we need to do because men do not ask questions. They do not ask questions. When they go to the doctor they are looking to

hurry up and get out of there...” The male observed, “and it is good to have two sets of ears... it is good to have somebody else in there with you...” the point made by these participants and others with similar sentiments is that there is the need for familial collaboration to achieve good health and PcA screening success.

### *Attempts to Understand the Risks for PcA in Men of African Descent*

A third factor that seemed to be associated with achieving a better understanding of the experience of prostate cancer screening decision making among West Indian American and African American men and their families was the attempt at understanding of the risks related to PcA in men of African descent. Inquiries about this risk came in multiple forms. They were made by women and men in the couples and men only group in multiple ways. Two examples come from an African American male and a West Indian American female in different focus groups but they represent the inquiries. The male noted his ignorance and his need to know by stating this:

That is one of the things at the back of my mind. But I don't think of myself as getting prostate cancer right now. I guess that I should be doing a little more studying to see if there are other things that I can be doing right now to minimize my risk later in life. I don't really know . I don't know the cause fir prostate cancer. I do not know the things that can be triggers that can be preventing or maximizing my risk for that. I don't really know if I am at risk for prostate cancer.

He continued later, “in terms of prostate cancer here is where I want to learn a little more that's why I want to hear other people's perspective...”

The female stated her inquiry in this way:

I don't know all that goes into prostate this whole , this recent surge in men being diagnosed with prostate cancer. I don't know all that goes into it. And I think I really have to , to , this awareness, I have to begin to pay a lot more attention. I have to pay a lot more attention to it. Whether its genetics, whether its

environmental, whether it's the result of lifestyle. I really don't know all that goes into it. But I would really, really like to know what are the factors that contribute to it.

These inquiries were typical of participants in almost every focus groups with different types of inquiries about the risks. There was also an expressed desire to do whatever is reasonably necessary to prevent PcA onset and achieve early detection if there is a diagnosis.

***Sensitivity to Cultural Patterns that may Compromise Capacity to Achieve Better Screening Experience***

A final factor that seemed to be associated with the participants achieving a better understanding of the experience of prostate cancer screening decision making among West Indian and African American men and their partners was their sensitivity to the cultural patterns that enhanced or compromised their capacity to achieve better experience with screening decision making. Multiple references were made about cultural matters that may or may not impact screening decisions among these participants. Many comments referred to cultural issues related to masculinity, views of homosexuality attributed to persons participating in DRE, and unwillingness to see the doctor, etc. These views appeared regular in focus group sessions. But one telling observation about fatalism was made by a West Indian American male in a couples group, he remarked:

With regards to fatalism, some people carry blame. They live with the belief that there is something that they did that caused this illness to happen to them. And sometimes they interpret it as a plague as something that I did over the course of time. And sometimes people do not even discuss it they say that I accept my fate and I will go down gracefully without accepting it or imposing it on other people. And they just go down and fade off the scene.

This remark captured the essence of multiple views on fate and fatalism that appeared in groups. It is a delicate but powerful cultural perspective that seemed to be repeated within the West Indian American community. Illustrations of fatalities were reported to support the power of this cultural occurrence.

The attempt to capture the perspective of participants in their imaginary journey into an actual diagnosis received multiple responses that included denial, proactive intervention, resignation, devastation, bringing a couple closer together to dealing with the PcA diagnosis as I dealt with other things, and I will do my best and trust God to see me through this challenge. One West Indian American male stated his perceptions this way that suggested denial and resignation upon diagnosis, here was his view:

It is either denial or it is as if when you find out that you have this disease its as if nobody lives with it. You understand? When someone finds out they have this disease they die. So when someone finds they have this disease if they think about it maybe they will die faster. So they may say let me just put it and the back of their mind and say let me live my life.

Another person, a West Indian American woman suggested proactivity including education and prompt treatment by observing:

After diagnosis I think that patient needs to be educated. I think we need more community involvement and tell the young men that they need to get tested because now they have so many kinds of new treatment. Because if they are being treated early ,because if they are treated early because a lot of people if they are treated early the prostate cancer do not really kill them now.

One African American male in a couples group agreed with the idea of proactive intervention and drew from his experience of survival from another type of cancer. He observed that he had a friend who refuse treatment and resigned to the inevitability of death. He reported this detail:

I have a friend that has prostate cancer. In fact he asked me early on about going to the doctor ad I was not the only one. But recently his wife had a big party for

him and he told me he said I just waited too late. He is still here right now but he knows that it is over. And the party he said this is the best thing that happened to me. He saw all of his family... People came from all over, people came from out of town and he said O.K. I am done. He said when I am gone I am good because as he said this is my party right now. He said I waited too late.

Some West Indian American men reported that they had a common friend in their church community who had a similar behavior and eventually died with no timely intervention.

Multiple men, both West Indian American and African American, reported the expectation of the experience of devastation if they ever had a PcA diagnosis. They seemed to consistently cite their fear of impotence and the inability to perform sexually. One man reported his experience as rooted in what his father related to him after he was diagnosed with prostate cancer. He related the incident by stating this:

You know my father passed away in 1998. He told me one day, I'll never forget what he said, he said because he couldn't perform anymore he felt he couldn't satisfy mom. They were married for over 50-years. And when he said it to me I heard him and I felt bad but I didn't understand. I knew him well enough to know that he wasn't afraid but because it was such a part of him. He had 8 kids, and he and mom were very close. It was coming out of him. She didn't love him any less, and she didn't care if he could perform or not. He felt bad for himself.

One West Indian American man expressed his concern very candidly as an issue of his own sexual desires and love for sex. He addressed the matter this way:

I think I never really delved into the area of the effects of prostate cancer on masculinity, virility, and whatever else. Stuff. It is good to know that I don't know if I am saying this right but for me it would be very scary because I like sex... so that's why I am listening hearing and I am saying this is something that I can connect with the need for all the information and so the diagnosis for me have me scared.

Another West Indian American male who was a PcA survivor shared his real life experience this way:

But you have summed up for all of us the sentiment because for me I love sex. That for me is the core of the fear of this illness. This illness affects that

experience to all of us. And it determines to a certain extent the treatment options that one chooses.

This perspective was offered by different men in different words as the groups were convened.

An African American woman in a couples group attempted to offer a terse correction to this limited view of masculinity by observing:

The same way we equate work with being a man then if we can build up those things and take the emphasis off the sexuality part. If that's directly tied to your masculinity. Let's say here there is more things to do that are better linked to being a man and we can play up those things. It might be very hard to do because there are many competing things that say that you are a man.

The issue of sexual performance was obvious an issue that revolved in the minds of the younger men and men in general more than was expressed among the women of the group.

With regards to the idea of a diagnosis bringing a couple emotionally closer together, different views were offered about this perspective. One woman observed "talk about these things so that you can feel close to your partner so that you talk" However, another observed that being brought closer was directly related to the quality of the relationship before the diagnosis. She observed "If you weren't having good communication a diagnosis may not make it so that it will draw you closer." She observed that the quality of the relationship was determined by the familial patterns before the diagnosis. She noted that "if you are not communicating especially on issues of health then a diagnosis will set in fear and stress and then ...all the other things start working in your mind and then you do cling to one another for support or you just shut down and clam up..." She concluded that a crisis in a couple's relationship "could easily go either way, but it could drive a couple together because sometimes a crisis does that".

Hence there were differing views about the effect of the anticipated diagnosis upon the couple relationship.

It seems as if there was no consistent single pattern of responses among the African American or West Indian American groups regarding their probable reactions to diagnosis of prostate cancer. It was, however, evident that the multiple perspectives aided in clarifying the experience of prostate cancer screening decision making among West Indian American and African American men and their partners. The apparent complexity of the emerging understanding of the experience suggests variability of responses to prostate cancer diagnosis with some elements of consistent similarity. This discovery may be helpful for persons engaged in family therapy and family health interventions.

In summary, the four factors of: a) effective means of achieving and maintaining good health in context of PcA challenges, b) heterosexual men and their partners in collaborative approaches to health maintenance and generation of appropriate PcA screening decisions, c) better understanding of the risks related to PcA in men of African descent, and d) concerns about culture based attitudes inhibiting adequate responses PcA threats were some key factors that seemed to be associated with participants efforts to reach the goal to better understand the experience of prostate cancer screening decision making among heterosexual American and African American men and their partners. Knowing and being attentive to these factors may also be helpful to researchers who are continuing efforts in seeking to understand their experience.



Table 2.

*The Five Main Themes that Emerged in Focus Groups about Understanding the Prostate Cancer Screening Decision Making of Heterosexual African American and West Indian American Men and their Families*

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**Uniquely Acquired Health Related Familial Conceptualizations:** *Health, self, and health maintenance conceptualized that participants acquired over time and state such in individualized and/or familial terms.* Health and health Maintenance are conceptualized by participants as individuals in inter-connected familial terms.

- Familial Health - Health Maintenance Conceptualized and expressed in familial relational terms
- Individual Stress – Stress is conceptualized in its impact on the individual
- Familial Stress and Health – Participants expressed a conceptualization of Health in familial terms
- Family Stress in Relationships – Participants expressed their understanding of stress impacts in relationships of immediate family and other relationships
- Health in Relationships - Participants’ conceptualization of health in terms of familial relationships
- Holistic Health – Participants expressed understanding and meaning of health in Holistic terms ; specific inclusive of relational impacts
- Health and Self Care – Participants reported an understanding of health as being proactive in self-care.
- Health Priority – Participants understanding of the meaning of prioritizing health maintenance
- Health and Stress - Participants’ conceptualization of Stress and its health effects
- Participants ‘conceptualization about interaction between Stress and Health

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**Familial Meaning Generated by Notions of Knowledge, Beliefs and Intentions:**

*Participants’ reports of aspects of their individual and familial experiences of the meaning of the PcA Screening decisions generated by individual and families’ notions of their knowledge, beliefs, and intentions*

- Health education learned over years
  - Trusted Health information gathered over time
  - PcA Knowledge assimilated
  - Trusted knowledge about PcA and PcA screening
  - Trusted beliefs about health and PcA Screening
  - Inaccurate knowledge – Participants’ trusted inaccurate information
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Table 2. *Continued*

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**Settled Mindset Conditioning Meaning of Experiences:** *Settled patterns of thinking about concepts that relate to prostate cancer and prostate cancer screening behaviors participants have inculcated over time that seem to condition participants meaning of experiences related to prostate cancer screening behaviors*

- Mindset about the role of the Supernatural in the cause and cure of PcA
- Mindset about the Source/cause of PcA
- Mindset about the trivializing of PcA Screening and PcA Diagnosis
- Mindset about the need for Secrecy in Dealing with PcA Diagnosis
- Mindset that suggests Resignation in Response after PcA Diagnosis
- Mindset about Beliefs surrounding PcA
- Mindset about Help-seeking Behaviors after PcA Diagnosis
- Mindset about invincibility in dealing with PcA Diagnosis
- Mindset about Fear affect after PcA Diagnosis
- Mindset of Fate and Fatalism in dealing with PcA Screening, PcA Diagnosis and Intervention

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**Meaning and Motivations Generated in Relationships Contexts:** *The nature of the relationships and interactions shared within families and between families and health providers, and health promoting parties and entities.*

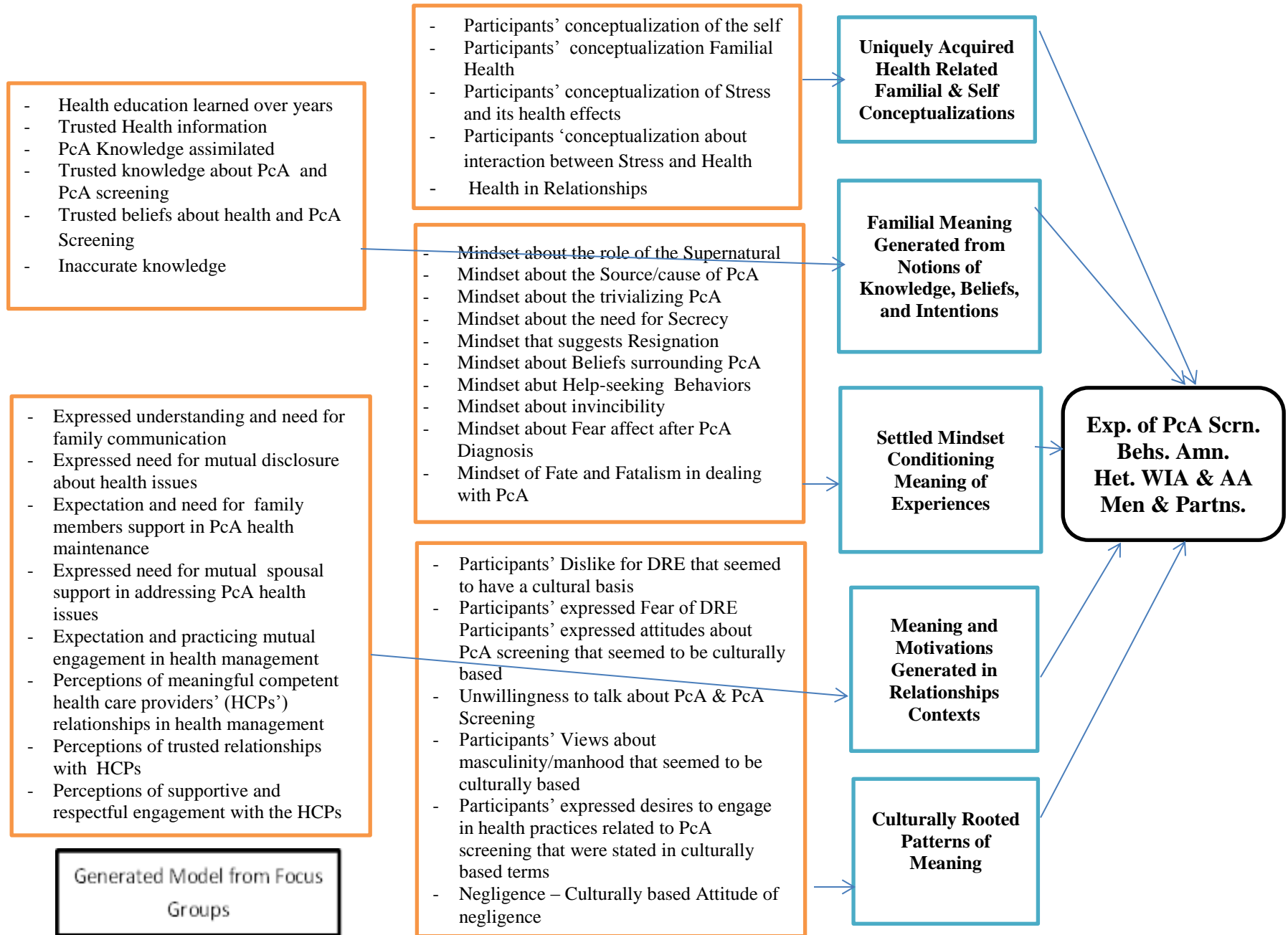
- Family Communication - Expressed understanding, commitment, and need for family communication
- Mutual Disclosure - Expressed commitment and need for mutual disclosure about health issues between Partners
- Mutual Support – Expectation, Commitment and need for Partners’ support in PcA health maintenance
- Expressed need for mutual spousal support in addressing PcA health issues
- Mutual Engagement - Expectation and practicing mutual engagement in health management
- Health Care Provider Relationships - Perceptions of meaningful relationships (regardless of the quality of the relationships) competent health care providers’ (HCPs’) relationships in health management
  - Perceptions of trusted relationships with HCPs
  - Perceptions of supportive and respectful engagement with the HCPs
  - Perceptions of exploitation and exploitative relationships with HCPs
- Relationships in terms of “highs” and “lows”
- Sexuality Relationships – Sexuality expressed in terms of relationships
- Male Relationships Disclosures – Disclosures about PcA Screening and PcA Diagnosis to men by men

Table 2. *Continued*

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**Culturally Rooted Patterns of Meaning:** *The nature of culturally transmitted beliefs, habits, customs and patterns that impact the meaning of PcA Screening experiences and decisions. They seemed to be shared beliefs, values, attitudes, and practices that are experienced by participants based on their cultural settings*

- Dislike for DRE - Participants' expressed Dislike of DRE due to Culturally related beliefs
  - Culturally Rooted Beliefs - Participants Culturally rooted Beliefs and thoughts about PcA screening / have a cultural basis
  - Fear of DRE - Participants' expressed Fear of DRE due to culturally based attitudes
  - Unwillingness to talk about PcA & PcA Screening - Participants' culturally based unwillingness to talk about PcA and PcA Screening
  - Negligence – Culturally based Attitude of negligence in PcA Health matters
  - Culturally Related Meaning of Masculinity – Participants expressed Ideas about masculinity/manhood that seemed to be culturally based
  - Cultural Positivity - Participants' expressed desires to engage in health practices related to PcA screening that were stated in culturally based terms
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## **Emerging Themes**

There were five main themes that emerged from the focus groups sessions as we attempted to understand the screening decision making process of heterosexual West Indian American and African American men and their partners. The themes were: 1) uniquely acquired health related familial conceptualizations, 2) familial meaning generated by notions of knowledge, beliefs and intentions, 3) settled mindset conditioning meaning of experiences, 4) meaning and motivations generated in relationships contexts, and 5) culturally rooted patterns of meaning.

### ***Uniquely Acquired Health Related Familial Conceptualizations***

Uniquely acquired health related familial conceptualizations refer to how health and health maintenance are conceptualized by participants as an inter-connected and/or familial set of ideas and meaning. Participants' perceptions of themselves and the meaning they attribute to issues such as health, stress, and views about the interactions between stress and health are generated or expressed in individually connected or familial terms. Connected with these conceptions are their views of the self. The participants' understanding of themselves and their capacity to function in society were also recognized in the data. Their understanding of stress and their capacity to deal with stress when it surfaces in their lives were often conceptualized in familial and relational terms. Similarly, they used familial/relational terms to describe their health responses when stress is manifested in their lives. The uniquely acquired meaning in health conceptualizations was derived from understanding participants' responses to questions

about their self-description, questions about their understanding of health, and questions about their understanding of stress and its impact on their health.

Examples of uniquely acquired health related familial conceptualizations included the meaning of health to the participants. For Alvin one African American participant (31 – 40) health was seen as “operating at a physical, mental, and emotional optimum or capacity...being able to have all these areas functioning well...at whatever condition that you are in...at maximum efficiency” was seen as health. Multiple voices stressed the holistic view of health with an important observation that the person or family had a responsibility to achieve good health. The responses tended away from an individualized understanding of health to a familial and interconnected understanding. They saw the meaning of the individual and family as partially related to the capacity of the individual and family to achieve and maintain health individually and collectively. John, an African American (31-40) stressed that health was “*the whole being. It is not just the mind but the whole thing. It is mentally, emotionally, and physically*”. Another asserted that health is “*accepting the benefits of what you get by living...enjoying the benefits of life*”

In articulating the familial dimension one African American male, James (61 -70) in a couples’ focus group asserted that health “is the well-being of the family.” Another, Kenrick (61 – 70) in the same group said that health is achieving longevity “feeling good, having everything functioning as they should”. Another African American man (61 – 70) saw health in context of the family as he said “health is the mental well-being of my wife and I; physical health where we have not pain...and eating well ... a balanced diet...”. Alex (51-60) in a West Indian male focus group saw health as a holistic concept in which he was “physically, well and emotionally healthy” and that he was “attentive to my

physical health and my relationship.” Gordon (51 – 60) in the same group observed that health to him was to “...see that my wife and children remain healthy...” The meaning of the self was not separated from the connection with the family as health was discussed. This is important because prostate cancer and the experiencing of prostate cancer screening decision making among heterosexual American and African American males and their partners is essentially a health issue. Consequently their cognitive attributions on health will likely have a bearing on the experience. One West Indian American woman Joan (51 – 60) in a West Indian American group said she saw health as “the complete state of well-being for yourself and your family. The absence of diseases...physically healthy, emotionally healthy, and spiritually healthy.” The holistic view of health and the conceptualization of health as a family ideal, with the understanding that personal and family health were things that people ought to work towards achieving were noticed in the focus groups of both African Americans and West Indian Americans.

Carlene, a West Indian American (41 – 50) noted that there are stressors everywhere “Personal, it’s on the job...it is not so much the stress but how we relate to it...” She proceeded to caution the group that people’s stress responses can be helpful or harmful to our health. Another West Indian American woman, Rebecca (41 – 50) observed that stress is often about how we respond “to the multitude of things we have no control over...if you focus on the things you have no control over you are liable to bring stress on yourself.” Stress was generally seen as negative and inimical to health and producing more stress on individuals and families.

The mental health dimension of health and the possibilities of poor mental health were addressed by multiple group participants. Elvin (West Indian American 41- 50) addressed very elaborately in one of the West Indian American men only focus groups. He observed that poor mental health is possible if there is poor health and other stressors resulting from various economic, social and medical stressors within families. He shared his own experience with illness and addressed the multiple adjustment issues he had to cope with together with anxiety, depression, and suicidal ideation. One of his key submissions was that mental health is a significant component of holistic health.

In the discussions about health and stress and the interaction between health and stress the couples and individuals saw themselves individually and/or collectively as couples and families had the capacities and responsibilities to manage their own health and their own stress responses. The stress management experience was seen as a couple and/or individual responsibility, hence the importance of this acquired meaning is the potential it has to impact the experience of prostate cancer decision making among the participants. For couples, experience would likely be impacted by couple's cooperative management of stress and health. In one African American group health management was seen as including dietary management, dietary discipline, medication management, active health management, attentiveness to one's own body, proactivity in health maintenance, and deliberate actions in seeking health care provider support for one's health management. James, in one African American men's group stressed the intelligent responses to health care providers and the intelligent management of one's own health. The conceptualization of the person's self as having the capacity to act responsibly to



produce beneficial results for the person and for the family seemed to emerge in the discussions.

The uniquely acquired health related familial conceptualizations theme seemed relevant to the understanding of the experience of prostate cancer screening decision making among heterosexual West Indian American and African American males and their partners in multiple ways. First, in the way in which health is abstracted as a holistic concept, second, in the way in which it addressed health as affecting all areas of the individual and family lives, third, in the way in which it viewed health maintenance as a collaborative familial responsibility, and fourth, in the way in which it saw the family as being the context with capacity to maintain family health. The fifth helpful idea is its notion that the experience of health is a familial experience while simultaneously thinking of health as well-being of the family. Sixth, stress was perceived by participants as a familial experience even if the onset of stress experience happens on an individual. Seventh and finally, there is the participants' perception of stress management as a familial responsibility that fits under this theme. These views of participants collectively contribute to a unique understanding of experience of prostate cancer screening decisions making among heterosexual West Indian American and African American men and their partners.

***Familial Meaning Generated by Notions of Knowledge, Beliefs and Intentions***

Familial meaning generated by notions of knowledge, beliefs and intentions refers to participants' reports of aspects of their individual and familial experiences of the

meaning of the PcA Screening decisions generated by individual and families' notions of their knowledge, beliefs, and intentions. Participants were apparently exposed to and/or acquired different types of information pertaining to health generally and related to prostate cancer more specifically. The information seemed to be of various types from multiple credible and non-credible sources. This information affected the meaning they attributed to familial experiences which may have in turn influenced their experience in prostate cancer screening decision making and their health related behaviors. Related to the knowledge base was the appeal for prostate cancer information also impacted upon their prostate cancer health knowledge. This was illustrated by such comments made by Henry, a younger African American male, (31- 40 –years-old) as “I am trying to get myself educated.” He was referring to health information and information about prostate cancer and the related risks. He continued later:

And I need to let some of those in my community, some at my age level or younger, know because we really don't...I need to learn about it. And so for me it is just being proactive about my health knowing that just like going into your teenage years you have to prepare. So going into your middle years you have to prepare, and going to your senior years you have to prepare. So I am trying to stay knowledgeable about health.

This participant, who had been in the military for over twelve years, was raising awareness to the fact that he had not been exposed to what he considered appropriate information about prostate cancer. The relevance of this detail is the manner in which this level of knowledge would logically influence his experience of prostate cancer screening decision making between this male and his partner. The notion of his intention to gain additional knowledge was evidently a part of his experience rooted in the familial meaning fostered by this intention.

Another perspective on this familial meaning generated by notions of knowledge, beliefs, and intentions was about the nature or quality of the information which participants trusted. One male participant referred to information about prostate health that he had seen on the television while another African American David (51 – 60) in the male only African American focus group talked about the availability of information on the internet. He remarked “we have the internet...just type in prostate cancer and you would see a whole lot of stuff coming up about prostate cancer, what you should do and what you shouldn’t do.” He made these statements to affirm the availability of information with no reference to the quality of the information. If information has any ability to impact experience through affecting attitudes and behaviors then it is plausible to see how the indiscriminate trusting of information will impact the experience of prostate cancer screening decision making.

There is also a type of knowledge that participants had about prostate cancer and about related issues such as prostate cancer screening (prostate specific antigen (PSA) and digital rectal examination (DRE) and other behaviors, practices, and issues that were related to the onset or amelioration of prostate cancer. The knowledge participants had about prostate cancer seemed to have contributed to the nature of their experience in prostate cancer screening decision making. For example, it would influence how they sought for additional information, impacted their own health education, and health behaviors. To illustrate this issue one African American male only focus group member, Henry, (African American 31 – 40) observed “when it comes to prostate anything I am clueless. You might as well talk Greek to me. I don’t really know.” The consequence of the level of knowledge was that their experience of health screening decisions and more

specifically the experience of prostate cancer screening decision making were potentially compromised. Their prostate cancer education and the health beliefs they had are also implicated by this reality.

Headley, another African American male (31 to 40) from one of the all-male focus group revealed his knowledge about prostate cancer by observing that he does self-examinations for prostate cancer. He said “I do the monthly shower checks to see if there are any lumps around that I need to be aware of...that is one of the things at the back of my mind. But I don’t think of myself as getting prostate cancer right now.” Here again is illustrated a case of inaccurate information about screening for prostate cancer affecting the experience of prostate cancer screening decision making among these men and their partners. In debriefing this participant revealed that he checked his testicles for lumps; confusing testicles with the prostate.

Participants’ appeal for knowledge and information refers to the appeal for information that participants appealed for during focus groups sessions. On multiple occasions participants in the focus groups inquired about the accuracy of information they possessed and or sought information about prostate cancer. For example Rebecca (41 – 50) a West Indian American Woman complained “I don’t know all that goes into the prostate cancer...this recent surge in men being diagnosed with prostate cancer. I don’t know all that goes into it and I think I have to begin to pay more attention...” James, an African American male explained that he had a friend who was diagnosed and in the late stages of the disease and thought that there was nothing he could do after diagnosed. He said his friend said “I just waited too late.” Christian, another African American (61-70) observed that his younger brother in his fifties who insisted that he is

too young to be dealing with prostate cancer questions he noted that his brother asked “aren’t you kind of premature in talking about these things?” Similarly Abraham a West Indian American (41 – 50) reported about his very good friend (41 – 50) who became assaultive with a doctor when the doctor did the first DRE on him during an annual physical examination without explaining to him what he was going to do. His anecdote indicated that his friend was completely ignorant about DREs even as he was over 40-years old.

Prostate cancer and prostate health knowledge referred to the knowledge base that participants had acquired over time. Contrary to previous observations, on occasions there were a number of men and women in both the African American and West Indian American focus groups who were knowledgeable about prostate cancer and the need for prostate cancer screening after age 40. Headley who thought he was accurately and necessarily doing monthly checks for prostate cancer was aware that he would need to be more attentive after he turned 40-years-old. In every group there were individual who knew and were ready to share with the group the understanding that 40-year-old was an important age for more aggressive screening for prostate cancer even if the knowledge did not translate into actual screening behaviors.

Inaccurate knowledge referred to the knowledge level of participants that was erroneous on multiple occasions even as participants trusted said information as correct. The consequences of the quality of knowledge that participants had previously acquired affected their prostate cancer screening decision making experience by influencing participants’ plans about health, in their beliefs about health and indirectly in their prostate cancer screening decision making experience. One older African American male,

as he sensed the need for accuracy of knowledge appealed to the men in the group to be proactive in achieving awareness of their bodies in order to achieve better medical visits and interventions, he stated:

I was going to say something because for me I know my body. My prostate was good forever and one day I couldn't urinate. I got a catater. No I had to go to the urologist. And that's how they found out the bladder problem. So you got to know your body and when things go bad don't just put it off. I could have said well I just can't urinate properly today and I could have put it off. So you have to know your body. The generated familial meaning also seemed to have an effect on participants' intentions.

Within the focus groups as information was shared men expressed willingness to change their behaviors and committed to more proactive approaches to their own health maintenance generally. There were instances of expressed intentions to specifically focus on prostate cancer screening behaviors thus impacting the experience of prostate cancer screening decision making. Gordon for example promised something that was illustrative of the health education impact:

So, when I say what I am willing to do I think I am willing to start relinquishing some of that self-doctoring that I do. And I am very much interested in finding out about things that you are talking about here. I don't even have a doctor, so that has been the impact that this has had on me. I know my wife has been trying for years to get me into this. So that is the effect that this has had on me. So I am going to go right out of this meeting and get a male family and follow up on this. I could go to wife's doctor. That's where she would want me to go. But I will get a doctor and I am going to try turning things around for myself personally.

Linked to the knowledge that participants had there were elements of beliefs that they had inculcated that were derived from the body of knowledge about health from their familial experiences. Their experiences of prostate cancer screening decisions were almost invariably influenced by their health beliefs. The idea was shared by one male group member in a couples group who cautioned that within faith communities people

may think that their lifestyle and their faith are protective of their health when this may not be so. He further stated:

I think we are sometimes disadvantaged that we are a part of that healthy living lifestyle community people. And while sometimes the dietary part of the lifestyle might be stressed – it's not even stressed a lot anymore. We might just feel comfortable that we are a part of that group... And so we might be putting more faith than active works into what we do.

He proceeded to assert that health may be undermined by beliefs that may be helpful but that are not followed up by healthy actions. This disconnect between acquired beliefs and actions serves to alert researcher to the fact that expressed appropriate beliefs may not independently positively impact the experience of prostate cancer screening decision making among West Indian American or African American men and their partners or with the population that the participants represent.

Within the context of the theme of familial meaning generated by notions of knowledge, beliefs, and intentions there was the coding that suggested that meaning was generated by participants' intentions and plans for various types of behaviors that were related to the experience of prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners. Intentions and plans for health behaviors related to visits with their medical doctors, prostate cancer education, prostate cancer screening practices, and other health care and health maintenance behaviors that participants plan for regardless of their following through to the actual behaviors. The planned behaviors apparently often came before the decisions to act. In the context of this study it was primarily the experience related to the decision to engage (or not to engage) in prostate cancer screening decisions (DREs and PSA testing) and decisions for other health behaviors that were related to prostate health

which were of paramount importance. Some of these decisions include decisions for prostate cancer interventions, health monitoring after intervention, and lifestyle adjustments after treatment.

David an African American (51-60) in one focus group expressed the need for planning one's behavior. He suggested that his plan included a detail in which once a year he would receive calls from his doctor's office to be reminded to come in for prostate cancer screening together with addressing other health care needs. He drew attention to two friends he was working with who refused to plan to get prostate cancer screening. He reported the danger of not planning and the resulting inaction in this anecdote:

I know two persons, who had prostate cancer. And the last one that died I asked him, how come you got to this stage? He said it was my fault. I didn't check. I didn't want anybody going up there and checking for me. And I am sorry now. A few weeks later he was dead. So I didn't want that to happen to me, so when the doctor wanted to check, I say go right ahead and check for me. They checked, they found something in the blood test, they did the biopsy and they found the cancer."

James, another African American male, insisted that the planning must come from the participants themselves and that they should constantly be aware of their own bodies. Planning needs also needs to be done with deliberateness to stay up on annual visits and in response to signals those participants bodies might be giving to them. He advocated for a more intellectual approach to dealing with health.

It seemed that in context of the theme familial meaning related to knowledge, beliefs, and intentions multiple aspects of knowledge, beliefs and intentions emerged that seemed to contribute to specific behavioral intentions which, all together influenced the experience of prostate cancer screening decision making among heterosexual West Indian



American and African American men and their partners. The decision making seemed to suggest that the experience may have results in appropriate screening actions for the families. The appropriate health screening decisions are *decisions* to participate in general health screening and particularly prostate cancer screening that included the PSA test and DRE screening.

The familial meaning generated by notions of knowledge, beliefs and intentions as a theme emerging from the focus groups suggested that participants acquired information, generated knowledge and beliefs over time that impacted their PcA screening decisions making experiences. They developed intentions to act in specific ways based on the knowledge and beliefs that they acquired. Their knowledge was occasionally derived from sources of questionable credibility but they had inculcated a body of knowledge and aspects of beliefs, and intentions that influenced the experience of prostate cancer screening decision making among heterosexual West Indian American and African men and their partners.

### *Settled Mindset Conditioning Meaning of Experiences*

Settled mindset conditioning meaning of experiences refers to the manner in which participants and families have settled patterns of thinking (mindset) that they have inculcated over time that condition the meaning of their experiences about PcA and PcA screening decision making. The emergence of this theme happened as participants reported patterns of thinking about PcA, screening behaviors and experiences related to both. There are multiple dimensions to this settled mindset conditioning meaning of experiences that included **a mindset about:** a) the Supernatural's role in the cause and cure of PcA, b) the source of PcA, c) trivializing PcA and PcA screening behaviors, d)

secrecy in dealing with PcA diagnosis, e) resignation after PcA diagnosis, f) beliefs surrounding PcA, g) help-seeking behaviors after PcA diagnosis, h) sense of invincibility in dealing with PcA, i) fear in dealing with PcA, j) fate/fatalism in dealing with PcA, and k) a relationship with a Higher Power in dealing with PcA.

The supernatural intervention mindset is a mindset that saw the causes and cures for PcA as supernatural activity over which a human has no control. One West Indian American remarked about a diagnosed person “He had a mindset that said if that is how God meant it to happen that’s how it was going to happen.” This illustrates a mindset that has a cognitive component that may makes a person’s experience in PcA screening decision making one of non-responsiveness. The source of PcA mindset was exemplified by a comment that asked a question and responded this way, “why is it that prostate cancer is such a black men problem globally? It seems to be the case. It is a spiritual problem. There is a shortage of black men as is. Some of them in prison and so on. I like to look at things in a spiritual way sometimes because they say we wrestle not against flesh and blood but against spiritual wickedness in high places”. This statement captured the essence of the source of PcA mindset. The trivializing of PcA and PcA screening mindset was revealed by the observation of one participant, “it happens a bit for some men the defense mechanism is to not get beyond the jokes of not screening...but for the general community of black men I think there is not serious conversation about the disease.”

There was a secrecy mindset that was also noticed in the data. It was a thinking that prompted a diagnosed individual to say “I will deal in secrecy with PcA”. The person intended to deal with the diagnosis in secrecy and concealed the information from

even his closest partner; his spouse. This secrecy mindset was indicated by two participants' comments. The first, "when we spoke to his wife she said he was bearing the burden since about 2008... when he was diagnosed and then when he was diagnosed he actually kept it a secret from his wife and kept it a secret from people." Another person from a West Indian focus group observed, "often you hear about people going through a crisis you will hear them say, "Don't tell my wife". These comments indicated a mindset that saw a benefit to concealment of their diagnosis.

A mindset of resignation also surfaced in the data. It suggested that a person saw a diagnosis as a condition that meant certain death and from which a patient could not recover. This mindset could be noticed in comments as the following from two focus group participants. The first was from a West Indian American male who noted that "one of the prevailing beliefs when you hear of the diagnosis of prostate cancer is that it is a death sentence. You start calculating. Oh, poor guy he doesn't have long more." The other comment was from another West Indian American male who said:

It is either denial or it is as if when you find out that you have this disease its as if nobody lives with it. You understand? When someone finds out they have this disease they die. So when someone finds they have this disease if they think about it maybe they will die faster. So they may say let me just put it and the back of their mind and say let me live my life.

These participants were observing a settled belief that concluded in a behavior of resignation of the self to the inevitable consequences of diagnosis.

The help seeking mindset refers to the mindset that a person develops that relates to his willingness or unwillingness to seek appropriate help for PcA screening or intervention before and after PcA diagnosis respectively. One West Indian American participant alluded to this mindset by stating the following:

After diagnosis I think that patient needs to be educated. I think we need more community involvement and tell the young men that they need to get tested because now they have so many kinds of new treatment. Because if they are being treated early because if they are treated early because a lot of people if they are treated early the prostate cancer do not really kill them now.”

The invincibility mindset was also discovered in the data it is a mindset that thinks of one-self as intrinsically capable of successfully dealing with PcA diagnosis without appropriate medical intervention. The type of statement that suggested this mindset is as follows, “...And for me they had an air of invincibility. And they would say ‘what’s that?’ And they just kept on living and they refused treatment...my assessment especially for my older uncle. It was a feeling of invincibility.” This report from a participant suggested a thinking that claimed intrinsic capacity to deal with PcA diagnosis.

The fear mindset was a pattern of affective response that made fear a dominating emotion after diagnosis or when facing the possibility of diagnosis. It was emphasized by one participant’s statement “There is a fear attached to it too. Fear.” And another’s observation, “...if someone is diagnosed. I think it would affect the family in different ways. Because first when you hear the word cancer like you get scared and people get angry...” Fear as an affective response may have debilitating effects on the experience of PcA screening decision making.

The fate/fatalism mindset regarded PcA diagnosis as an inevitability. This is a mindset that thinks of PcA diagnosis as a matter of fate with which one has to live and has no capacity to avert. One simply has to deal with its consequences. The fate/fatalism mindset was observed based the expressed thinking reported by participants two illustrative statement are, “...well in the example that was cited we noticed that early to

him this was fate and he accepted it and just decided to go along with it". The second statement was "they live with the belief that there is something that they did that caused this illness to happen to them. And sometimes they interpret it as a plague as something that I did over the course of time." Here is also seen a mindset that would suggest a relinquishing of efforts to deal with PcA through screening and appropriate interventions.

There was also a higher Power relationship mindset that was seen in the data it is understood as a pattern of thinking that a participant reported that suggested dealing with PcA through one's relationship with a higher power. Two participant statements seem to indicate this mindset. The first said "and sometimes we even shut God out and we put up these barriers and we are inside like a cell." A second statement was "Sometimes for me, God is my stress reliever. If I pray about the situation and sometimes he works it out... I am really not trying to work things out on my own."

The settled mindset that conditions the meaning of meaning of experiences emerge from deeply rooted patterns of thinking that seem to contribute to an understanding of the experiences of prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners. The mindset suggest a cognitive state that proximally affects attitudes and behaviors related to the experience.

### ***Meaning and Motivations Generated in Relationships Contexts***

Meaning and motivations generated in relationships contexts refer to the nature of the relationships within families and between families and health related parties and entities. The relationships within families and between families and health care providers

generate meaning and motivations to the family members. Familial relationships refer to relationship and relationship quality that exists between couples and within families. It is indicated by the communication patterns between couple and within family, their sense of family commitment in support, their report of mutual spousal support in health management, and their willingness to disclose details about life in general and about health matters (particularly relating to PcA screening and PcA) within the marital relationships or the relationship with the significant others. Outside of the immediate family circle there are other relationships which exist with family members. Relationships with health care professionals, health care entities, and co-workers are examples of such extra-familial relationships that participants maintain. Meaning and motivation are generated in these relationships according to these data.

There were multiple aspects within the coding that coalesced around this theme of meaning and motivation in relational terms. The coded aspects of the relationships are as follows: a) shared responsibility for health, b) commitment to familial communication particularly about health matters, c) expressions of familial mutual disclosure, d) mutual engagement and mutual support on health related issues, e) health care providers/entities (HCP) relationships, f) experience of “highs” and “lows” in familial relational terms, g) expressions of sexuality in relational terms, and h) communication/disclosure to male friends about PcA issues in relational terms.

Shared responsibility for health management within the family refers to an expressed commitment of partners to share in their mutual health management. This seemed to be a phenomenon that frequently surfaced within the groups. James and his wife indicated that they had shared responsibilities for each other’s health management

just as they share responsibilities for everything else that they dealt with over the years of their marriage. They reported a constant dialogue that accompanied the pattern of shared health management. In this group of couples Ms. James responded to an inquiry about sexual difficulties for men diagnosed with prostate cancer by observing that in a committed relationship the “wife would be understanding and work with the male partner through the difficulties.” The Ectrains (West Indian Americans) shared the same view about shared health management as they observed their experience of nursing the husband through a procedure to deal with a heart condition. The Corbins alerted the group that this was the same in their family as they said they were constantly supporting each other as they dealt with health maintenance for the family. Carlene (a nurse) observed that she dealt with her husband’s doctor in instances when she felt something was missing in the service her husband received.

In understanding familial relationships some additional issues that seemed to surface within the groups included spousal support, consistent disclosures to spouses, and the experience of comfort in disclosing health information. It seems as if these were all aspects of quality of familial communication. Familial communication refers to the reported commitment to or practice of engaging in familial communication particularly on health related/PcA matters. This seemed evident in group members’ responses when the men of one African American couples group reported that if and when they were diagnosed for prostate they would/did disclose first to their wives. The willingness to disclose in this manner may be a statement about the ongoing quality of familial communication. Miriam (African American 51 – 60) suggested that:

If you weren’t ...having good communication a diagnosis may not...draw you closer. Because if you are not communicating especially on issues of health then a

diagnosis will set in fear and stress and then you know then all the other things start working in your mind and then you do cling to one another for support or you just shut down and clam up.

She suggested that a diagnosis could have negative effects on a relationship if communication was poor before the crisis of diagnosis. A male group member of another couples group also addressed the importance of communication within the family by observing:

As a family we have to have communication to help deal with health issues...we talk about that in our family. Not all families do that. But we know what sickness to look for in our family so we would let the girls know we would sit down and say don't eat that because it does that to our family. I think that helps but it is to get the family to sit down and talk about ...the problem.

Gender differences surfaced in the discussion as men indicated that they were very willing to hear their wives talk about their (wives) health and very willing to address their wives health and the children's health issues while admitting that they were unwilling to discuss their own health issues. Gordon illustrated that when he said:

In my specific case my wife has expressed concern but not that I listen to her at all. ..But she is the one that raises concerns about the issues...I try to leave the subject as fast as I can. Unless we are dealing with issues pertaining to her or the children or something..."

This pattern was discovered particularly among West Indian American men.

In these familial relationships we may perceive that the relationships impact the experience of prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners. Such indicators of relationship's quality as communication, mutual disclosure, mutual concern, and shared responsibility in health management and health maintenance together or as individual aspects of familial relationships may/will contribute to the nature of the prostate cancer screening decision making experience among couples.



There are also relationships between participants and health care related persons and entities such as doctors and other health care providers that seem to influence participants' experience in prostate cancer screening decision making. Specifically, their willingness to engage with the Health care provider (HCP) and the health care system seem to be the concern. The relationship between participants and these persons/entities seems to be nurtured and influenced by participants' perceptions of their trust of HCP, of the competence of the HCP, of support/non-support received from the HCP, of respect received from the HCP, and of exploitation received from the HCP. Some of the difficulties inherent in the participants' relationships with the HCP seemed to be culturally based and transmitted.

Henry (31-40 African American) observed that he has a distrust of doctors even after serving in the military where health checks were mandated. He stated it this way:

Out here, with no one putting the proverbial "gun to your head"... but it is unfortunate, in the surrounding area that I live, it does not come up. It is something that is internal that you have to take from radio, TV, and then say o.k. I will do this and then follow through with it. It has been very hard for myself because of trust issues with doctors. Military doctors once again you don't have a choice. Out here they are so many. Which ones do I go to? Which ones can I afford? Which ones do I trust?

This lack of trust as will be noted later is culturally based but Kenrick, (an African American 61-70) affirmed in a couples group the deep seated lack of trust for doctors within the African American male community. Gordon (51-60 West Indian American) reported the development of distrust between him and his doctor after one experience which he described this way:

It was 10 years ago that I had been going almost every year to... (my doctor)... and he is the one that I would make my appointments to see. ... So I will always go and see him. And you know we will sit down, have a discussion, he makes his notes, they draw the blood they check the cholesterol; I would come back a

couple a weeks and then discuss it and so on. Then one day there was a change. He said let us go over into the other room. I couldn't figure out what we were going into the other room for. No idea. Then he said 'we are going to go for the gold now' (group laughter). I had no idea of what he was going to do. That was my last physical in ten years. So it is a really big thing for me to tell you guys that I am willing to go back.

Here the HCP relationship with the participant was undermined by distrust which revolved around improper, inadequate, and/or insufficient communication between the health care provider and the participant. An innocent comment and poor communication resulted in distrust of the doctor and poor relationship between the doctor and the participant. Brian (West Indian American 51 – 60) made his observation of his own experiences which contrasted with each other because the different doctors treated him differently. On the one hand he said:

When I went for the physical examination, the doctor he was a Korean guy, and when he came to that part he said, "drop you pants" when I did that he said "bend down" and after that I felt a sudden pain. It was so rough and uncouth that afterwards when it was finished I sat down on a bench and cried because it hurt so much.

He refrained from anything of the sort, any type of similar medical attention, until many years afterwards when he reported a different type of experience in which respect and communication accompanied the visit and intervention. It seemed to have made a great difference. He said:

Then years later, I changed doctors and I got Dr. Bradley. Then he said we have to do that. Then I said no we are not going to do that thing. It hurts. Then he talked to me. I said we are not going to do the blood test? He said yes we are going to do the blood test but with the blood test we can miss stuff. Then he explained the things to me. Then he was the opposite of that (first test) he was the opposite.

Kenrick, added the view that the way the medicine is currently practiced some of the issues of exploitation, lack of respect of the participants, and insufficient one-on-one

interactions between physicians and patients result in more distrust of the health care provider and a compromising of the relationship. Clorine, a West Indian American (51 – 60) asserted that many people are uncomfortable with their doctors and offered suggestions to deal with such discomfort she stated:

I think another thing is to be comfortable with your doctors. I know in doing research that I need to have a plan for my visit with my doctor. I know that when you go to the doctor there are visits some are 10 minutes, some are 15 minutes, some are 20 minutes and some are 45 minutes. But when you go in there for a physical if you do not have anything to say if you do not have anything prepared the doctor will just come in blah, blah, blah and just gone. .. But if you know what questions you are going to ask your doctor you will build a better relationship and you will be able to know more about your body and will be able get better treatment.

Health care provider relationships are evidently seemed to be affected by multiple realities which cannot be left unattended in health matters in general and in addressing the experience of prostate cancer screening decision making experience among heterosexual West Indian American and African American males and their partners that this research addresses. As we recognize the factors that contribute to the quality of the relationships between participants and their health care providers we would need to accentuate the factors that help in the relationships functioning positively for participants.

Group members offered suggestions that may be characterized as a) intelligent responses to health care providers, b) deliberately seeking health care provider's support, c) participants need to be deliberately building health care provider relationships, and d) participants engaging health care providers' efforts in participants' education about health; be ready to ask and talk to the HCP. These suggestions seemed to be plausible options which, if implemented will contribute to the enhancement of the experience of

prostate cancer screening decision among heterosexual West Indian American men and their partners.

Meaning and motivations generated in relationships contexts was also illustrated in participants understanding of “highs” and “lows” in their lives as matters of relationships. This thematic consistency was manifested in their expressions of “highs” and “lows” in familial relational terms. For example, one African American male spoke of his experience in this way:

My highs is really when my family is at the best in coordinating, especially when we are on a spiritually high level. When we are there together it brings me most of the highs in my life. And most of the lows is opposite. When we not going in accord.

He saw familial relationships in his experience. Similarly, a West Indian American male seemed to concur, “My high is when I met my wife when we fell in love Those were my highs. ...when io got married, when I first had my daughter, and felt that .. the first child when you felt that feeling it’s a feeling like no other.” The expressions of “Highs” and “lows” in familial relationships terms seemed important to the researcher because this conceptualization illustrates participants’ proclivity to important things in relational terms. It, therefore, seems that PcA and PcA screening, if conceptually elevated to importance may also be easily be seen in familial relational terms, thus connecting with the experience of prostate cancer screening decision making among West Indian American and African American men and their partners.

The final item that seemed to code well and appeared compatible to the theme of meaning and motivations generated in relationships contexts was the construct of sexuality in relationship to PcA diagnosis. This code refers to participants’ expressed understanding of compromised sexuality due to PcA diagnosis. Their understanding of

the meaning of this compromised sexuality was expressed in relational terms. A few examples of male comments during focus groups are the following. One West Indian American offered this perspective, “Guys, gentlemen I can’t explain once you are dealing with prostate cancer issues for the first time in your life sex becomes an important issue and that is a whole different dimension all by itself.” Another African American male observed, “Some people do not want to know. Because of the fear of something. It might be the fear of sexuality and poor sexual performance. That is something that is out there pretty much. And so some people do not want to know and to deal with that reality.” Another African American male observed another detail about the embarrassment compromised sexuality may cause:

And some people kind of deal with it in another way. Some people are embarrassed to say they have prostate cancer because some people like me thought that when people have prostate cancer their sexuality is gone. So that is not something that you want to be out there. So you have it you try to keep it quiet as a secret.

These views were all tending in one direction which seemed to be summarized by an African American male in a couples’ group who was deliberately succinct:

You know my father passed away in 1998. He told me one day, I ‘ll never forget what he said, he said because he couldn’t perform anymore he felt he couldn’t satisfy mom. They were married for over 50-years. And when he said it to me I heard him and I felt bad but I didn’t understand... It was coming out of him. She didn’t love him any less and she didn’t care if he could perform or not. He felt bad for himself.

Sexuality is almost invariably conceptualized by men in relational terms and the meaning of sexuality or compromised sexuality may resonate in a very impactful manner within the context of the experience of prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners.

Meaning and motivations generated in relationships contexts as addressed in this section addressed multiple types of relationships that contribute to the meaning of the experience of prostate cancer screening decision making among West Indian American and African American couples. Familial/dyadic relationships, individuals within the health care community relationships, and life experiences within a relationship context are evidently impactful in the PcA screening decisions making experience.

### *Culturally Rooted Patterns of Meaning*

Culturally rooted patterns of meaning refers to the nature of culturally transmitted beliefs, habits, customs and patterns that impact the meaning of the experience of PcA screening decision making among heterosexual West Indian American and African American men and their partners. These culturally rooted patterns seemed to be the communally shared beliefs, values, and motivations that were reported by the participants. These patterns of meaning seemed to be prevalent in their cultural contexts and were apparently transferred to them from previous generations. Within the participants communities these subjective beliefs, values, and motivations also relate to beliefs and values about health. These beliefs, values, and motivations would typically impact their psychological processes such as their thinking, feelings/emotions, and their intentions about health behaviors. The culturally rooted patterns directly and indirectly impact their health behaviors including prostate cancer screening decisions and screening behaviors.

The culturally rooted patterns of meaning seemed to emerge from the following codes: a) dislike for DRE due to culturally rooted beliefs and thoughts, b) culturally

rooted beliefs and thoughts about PcA screening, c) culturally based fear of DRE, d) culturally rooted unwillingness to talk about PcA and PcA screening, e) attitude of negligence in dealing with PcA health matters, f) culturally related masculinity, and g) cultural connection to food. The multiple issues that are the bases of the culturally transmitted patterns as per the participants' reports seemed to include a history of slavery and oppression, historical realities of medical malpractice, transgenerational patterns, and societal mores and values.

Dislike for DRE due to culturally rooted beliefs and thoughts refers to a stated dislike for DRE due to historical culturally based beliefs and experiences. One West Indian American female in a couples' group when probed about the reason for her intervention to get a DRE done for a male partner offered this perspective: "...and I notice that most men do not like to have this test done on them. As a nurse I notice that when I talk to men about this they say "I don't want t no doctor to put their hand up in my butt". A West Indian American male in a couples group offered this opinion that endorsed a similar view, we do not like the fact that nobody whether it's a man or a woman pushing something up their butt..." The dislike for the DRE is clear based on these participants' comments.

Culturally rooted beliefs and thoughts about PcA screening refers to a stated understanding of participants and their community's responses to PcA Screening that suggested culturally rooted reasoning. A similar construct, culturally based fear of DRE refers to fear of DREs based on culturally rooted beliefs and ideas. One African American woman in a couples group made tis terse observation:

Now when it comes to our black men because of the history of slavery and everything else the degrading that black men went through the black men have

that homophobic attitude. I am not gay. Therefore for a lot of black men they would not get pass that. So they won't go and get the test.

Kenrick, an African American male in a couples group, spoke about the history of slavery and oppression as the root for some of these cultural patterns and said:

A lot of this is history. People forget that in America the institution of slavery kept a lot of these things...we couldn't educate ourselves, we weren't able to learn, we weren't able to read. It wasn't until 1954 when Dred Scott, when the decision was made for us to be able to go to school again after segregation that we could actually learn. So, 50 years ago, 60 years ago. So what we are discussing there were barriers put in place beyond our control where we couldn't. it was against the law for a black man or woman to be educated. We couldn't get to read or write. We had to be ignorant. And because of that last century we have just gotten out of that now we are supposed to know how to take care of ourselves?

The fear of DRE was endorsed by the view of one West Indian American male who expressed his thoughts this way, "Caribbean men do not want to have anything to do with that region of the body. "

Culturally based unwillingness to talk about PcA and PcA screening referred to a reluctance to talk about PcA and PcA screening based on historic culturally related patterns of behaviors. This tendency surfaced in discussions. For example, one West Indian American woman reported her experience growing up in her place of birth by noting,

I was going to say, I mean growing up on the island people did not talk about prostate cancer. Growing up as a kid I would hear people say '*oh he have boason*'. I never knew what that word means. But it is enlarged prostate or something like that. Its when I came to America I understood what that meant.

An African American woman in a couples group observed that it is a problem with men in particular she said

I don't think they talk much about it (prostate cancer) at all. Men don't talk about it at all. Maybe a few men would or could get together at church and talk about it which would be a very healthy thing to do; young men and older men as well. But I think men just don't want to talk about it.



She was addressing the issue of men communicating about prostate cancer within the African American community. Silence on an important topic and unwillingness to talk will likely contribute to the experience of prostate cancer screening decision making.

Clement (African American 71 – 80) observed that there were familial patterns of not having much to do with doctors and unwillingness to talk about matters pertaining to sex organs by observing this:

As a matter of fact when I was a kid the only time you went to a doctor to talk anything about your privates was when you thought you had a disease. Other than that you don't talk to the doctor at all about that. You just go see him and he gives you the diagnosis or whatever. What's wrong with you? And that was it.

Culturally rooted attitudes of negligence in dealing with prostate health referred to participants' reports of an unwillingness to participate in PcA Screening due to a cultural pattern of negligence about health matters. Other participants from African and West Indian American groups observed that historically there were familial habits of not engaging the doctor until one was sick. Abraham (West Indian American) cited a recent experience that he and other friend had of a man who recently died after an illness with prostate cancer in which he refused early attention and then refused medical intervention because of lack trust of doctors and unwillingness to see the doctors. One African American participant in a couples' group observed the bravado that existed from not visiting doctors and visit was only because you were sick he noted:

If there is not a lot of deaths from different diseases, then you start to think that you are gifted you are not a quick person to run to the doctor. Then you have to address things culturally. In fact it is not something in my culture where you go to the doctor only if you are sick. You do not go to the doctor if you are not sick. You don't go before you get sick.

A recurring concern was the claim that men of African descent, West Indian American or African American had culturally based resistance to prostate cancer screening. Aldis (West Indian American 41 – 50) remarked that:

Now when it comes to life and death on this matter you would put aside all things but this not something men want. This is not something comfortable at all. I am sure all the men who came here yesterday at the health fair) if you told them come go in this room here and do that examination they would not want that.

It seems that the experience of prostate cancer screening decision making among heterosexual West Indian American or African American men would naturally be impacted by this cultural orientation. In every group the culturally based resistance to DRE's was noted.

Another specific matter pertaining to culturally based patterns of meaning was the issue of masculinity for men of African descent who were present in the focus groups. Culturally related meaning of masculinity referred to participants' reported views of masculinity that are culturally generated. There was an insistence that this procedure (DRE) was viewed as a compromising of one's masculinity or an indictment on one's sense of manhood. In every group reference was made to the fact that this was a view within the African American/West Indian American Community. The view also included the idea that willingness to participate in DREs was a statement about one's sexual orientation (suggesting that the participating patient was gay) and as such had a negative connotation to it. David observed that

Some people ... say, like one guy said to me if he goes to do the DRE, the doctor might be gay and might get sexual urges for him and may want to be very intrusive in his body and things like that..." He admitted that this view might be extreme but suggested that it is a view that is out there.

An interesting alternative to this view was the disclosures of men in the focus groups who had been diagnosed with prostate cancer. These men indicated their fear of prostate cancer, fear of treatment interventions, and fear of poor recovery were all rooted in their morbid fear of losing sexual capacity. Elvin (West Indian American 41 - 50) observed:

Success rate of sparing the erectile functioning nerve and that was important because at the early 40s with most of the fellows in the group said doc what you are doing here ... I was terrified because I am a young man I have a wife and I have many, many more years to go before I start thinking about impotence...

His contribution to the group included another observation in which he stated:

When you talk about mental health and then you talk about sex as a young man with a wife. Guys, gentlemen I can't explain once you are dealing with prostate cancer issues for the first time in your life, sex becomes an important issue and that is a whole different dimension all by itself.

The researcher's observation was that this dimension to the discussion had a significant impact on the men in the room this being an all-male focus group. The noteworthy issue was that in the context of the culturally rooted patterns that led to non-participation in screening behaviors based on perceptions of compromised masculinity may be well counteracted by observations from the lived experienced of other diagnosed men. They are able to speak of real compromising of masculinity (poor sexual functioning) if men do not engage in proper screening that can lead to early detection and adequate interventions and recovery. For example an African American male from a couples group observed how the teaching of younger men about prostate health and encourage the screening experience can be positively impacted and achieved, he suggested:

Not like O.K. the book says this. No you have somebody like me or whoever it is who had it before or have it. Let them talk about it and the experience that they

had when they were diagnosed. Let them talk about how they felt when they were diagnosed with it you know. Not to scare them but to let them know the importance of being able to check early. Early diagnosis. My diagnosis you know is in the early stage... If you check and get early diagnosis you will have a chance. A lot of people do not know that if it is detected early you chances of getting rid of it are great. A lot better.

The point of a diagnosed individual or a PcA survivor being engaged in educating of other men seemed to be a useful option offered by focus groups. An African American woman suggested that the churches can also coordinate educational efforts for the young men, her observation was, “I think the churches can play a big part in the men’s groups and things like that. ... the boys do not have anybody to talk to but for the men in the church. The church can play a big part in talking with these young boys at an early age.”

These two options of education sponsored by churches and community organizations and the active participation of prostate cancer diagnosed and PcA survivors in serving in the education of men about PcA screening decision making seemed useful. These are probably very practical and helpful means of addressing the experience of prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners.

Culturally based patterns of meaning as an emergent theme from the focus groups seemed to capture elements from the patterns rooted in slavery and oppression, an unwillingness to engage with the medical doctors, unwillingness to engage doctors within the family contexts, the cultural resistance to participation in DREs, and the stigma of being gay and the homosexuality aura surrounding DREs. These patterns undoubtedly contribute to the experience of prostate cancer screening decisions of the participants and other members of the population they represent.

The thrust of this section was primarily to observe that there is a perception that a part of the phenomena that influence understanding and interpretation of health related decisions and responses were rooted in cultural patterns that are beliefs, values, and practices that are socially shared and may have been transmitted from one generation to the next. These focus groups data indicated that these cultural patterns of meaning are related to the experience of prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners.

### **Differences and Similarities between the West Indian American and African American Men**

Within the West Indian American community there were reports of unwillingness to visit doctors directly resulting because of a negative experience with a particular doctor, as was noted in the cases of Gordon and Brian. They had an experience that suggested incompetence, disrespect, and even injury resulting from the interaction with the doctor. Their interaction with doctors thereafter were few and only when determined to be absolutely necessary. On the other hand, within the African American Community as these participants reported the unwillingness to engage with health care professionals were not based mainly on actual experiences, though there were a few reported. Their unwillingness was due to their distrust based on a history of abuse and stories of abuse of the African American male population that were transmitted from generation to generation.

There seemed to be similarities in the views of both groups regarding unwillingness to engage with prostate cancer screening. They perceived that there was

something that diminished or impugned masculinity if and when the DRE was done. Appropriate health education and health care provider relationships seemed to motivate both groups to participate in prostate cancer health screening.

Even though there were culturally based resistance to PcA screening behaviors and unwillingness to engage with medical providers as information and education on prostate cancer issues were received through various channels, the willingness of both groups to participate in screening behaviors improved. There was also reported enhanced responsiveness to new and more accurate information about health in general and about prostate health in specific; responsiveness that may result in more screening behaviors.

### **Contribution of Study to the Field of Marriage and Family**

#### **Therapy**

This study has the potential to contribute to the field of marital and family therapy by enhancing the understanding of the experience of decision making by heterosexual couples in dealing with preventive behaviors of prostate cancer screening and possibly to help understand screening decision making for other chronic illness in families. It may also help to achieve better understanding of West Indian American immigrant population, by better explicating the problems of the experience of prostate cancer screening decisions in heterosexual West Indian American/Caribbean American men and their partners.

This study also contribute to the knowledge of how to help in the prevention, early detection, early intervention, more effective treatment, and better recovery from prostate cancer and/or other chronic illness. While most chronic illnesses have important

implications to family functioning prostate cancer potentially has more important implications than many other illnesses because of its additional direct impact on the important area of family sexuality, conceptions of masculinity, perceptions of marital quality, and overall quality of life of the diagnosed heterosexual individual and his partner. As such, this study has the potential to offer significant information about family and insights for treatment in family therapy. It will enable the enhancement of models to do clinical practice with Caribbean American immigrant families.

### **Contribution to theory in Marriage and Family Therapy**

The theoretical understanding and perspectives of dealing with illness in marital and family therapy, particularly in the area of medical family therapy is constantly experiencing improvement. This study will contribute to the improvement of theory in the field by clarifying the theoretical understanding of the functioning of West Indian American families and serve in enhancing the understanding of agency and communion of the families within this population group. The particular improvement of theory will be to understand better how this sector of the population addresses health related decisions and the corresponding experience associated with such decisions. It helps clarify how they negotiate the health care system, demonstrates the nature of the information that they use to negotiate the health care system, and the nature of the knowledge of this disease in specific and knowledge of disease in general that guides their decision making and impacts their decision making experience. This work will also add to the theory by augmenting the understanding of how West Indian American/African American men and

their families utilize family connections to improve dealing with prostate cancer and other chronic illness challenges.

In context of this research general principles may be derived which may be incorporated into a systems perspective about the nature of the interactions affecting the experience of prostate cancer screening decision making between heterosexual West Indian American males and their partners. An enhanced systemic treatment model can evolve that should minimally include addressing the symbolic, affective, and sensate dimensions of interactions (Heiman, 2007). A better understanding of the symbolic, affective, and sensate levels of interactions may be better clarified by this work. So first, at the symbolic level of interactions people in relationships exchange words, symbolic gestures, and other cognitive representational features. At this level of interaction there must be a significant level of congruent cultural background in order for them to be able to experience understanding during their exchanges and interactions. These are the shared understanding of meaning. The commonality of understanding and shared meaning may be an important space that for interventions, to find access to people in relations, to understand and adjust the experience, and to enhance screening decisions and screening behaviors.

Second, the affect-regulated interactions that this research may enhance are descriptions of the expressions and perceptions of affect distinct from the symbolic level just described. In a situation of the experience of prostate cancer screening decision making in which sexuality and sexual functioning are implicated, affect regulated interactions will be activated and noticed. This research can help clarify sexuality's emphasis on arousal, desire and non-verbal communication as aspects of affect-regulated



interactions. The prostate cancer screening decision making experience seems to be part of the sexual context of meaning that is at the affect regulated level. Interactions which, at the symbolic level are apparently related to sexuality will very likely at the affect-regulated level have a bearing on couples screening decisions experience. This is another level of meaning contribution that this research logically contributes to marital and family science at the theoretical and therapy levels.

A third level of the interaction will be at the sensate exchanges and interaction level. This is the level of interaction that refers to sensory, neurophysiological responses and motor reflexes that each partner elicits from another in relationships. This research suggested that familial meaning is generated in relationships contexts. Heterosexual men of West Indian American and African American heritages can be guided into better relationships building with partners and with professionals that can contribute to the enhancement of functional meaning in these aspects of their relationships. Better relationships can logically provide opportunity for improved experience at the sensate interaction levels.

Additionally, this research offers a framework for therapists by suggesting a framework for thinking in therapeutic intervention for heterosexual West Indian American and African men and their partners dealing with prostate cancer screening decision making issues. The research suggests, first that there are uniquely acquired familial health conceptualizations that may be important for family therapy as therapist provide therapeutic interventions in dealing with families and prostate cancer issues. The idea that health is conceptualized in familial terms suggests that in addressing health matters of the individual it is important for deliberate inclusion of all available family

members in health related therapeutic issues. Secondly this research contributes to therapy by raising awareness of the importance and utility of knowledge and beliefs from client's perspective as therapeutic work is done with clients dealing with PcA screening and PcA health issues.

Third, this research brings a spotlight on the need for seeking, clarifying, and understanding the mindset of clients from this population to discover their patterns of thinking about PcA health and PcA screening concerns specifically and therapy related issues generally as therapeutic work is done with them. A fourth perspective that this research offers to therapists is the need for attentiveness to the nature and quality of relationships that clients from this population have cultivated. Their relationships offer them peculiar experiencing related to their meaning attributions and motivations. This would be needed because meaning and motivations are generated in relationships and understanding these relationships may be useful in helping to unlock and generate motivations and insight for clients. Finally, this research contributes to theory and family therapy by offering a unique perspective to the role of culture in the PcA health experience of heterosexual West Indian and African American men and their partners. There are certain culturally based patterns of meaning that for the underpinnings of meaning attributed to multiple PcA related phenomena that marital and family theorists and therapists need to be willing to remain attentive and to explore further as work is done in this population.

## CHAPTER SEVEN

### DISCUSSION

Information obtained from six focus groups of African Americans and West Indian Americans a sector of the American population at increased risk for prostate cancer with lived experience (lived experience - the ways in which people make sense of their experiences and the meanings they ascribe or attribute to them t observes their choices and options and observes how those factors influence their perceptions of knowledge, it is the personal and unique perspective of the participants and reveals how their perspectives are shaped by subjective factors that they identify such as race, class, gender, sexuality, religion, political association and other roles and characteristics that determine how people live their daily lives etc. (Boylorn, 2008) yielded a model that illustrated the experience of prostate cancer screening decision experience within the West Indian American and African American community. Participants seemed to have a goal of understanding the experience of prostate cancer screening decisions of heterosexual WIA and AA men and their partners. In the view of the researcher a examination of the model and its components reveal some key concepts and components that are useful in understanding the experience of prostate cancer screening decision making process of heterosexual African America and West Indian American men and their partners. The model suggests an ultimate goal of prostate cancer and health screening behaviors.

The factors that seemed to contribute to the participants goal of understanding the experience of PcA screening decisions among WIA and AA men and their partners were: 1) attempts at achieving and maintaining good health, 2) partner collaboration to address

health and pca screening success, 3) attempts to better understand the risks for pca in men of African descent, and 4) developing a sensitivity to cultural patterns that may compromise capacity to achieve better screening experience. After open and axial coding the constructs were organized into five emergent themes which were: 1) uniquely acquired familial health conceptualizations, 2) familial meaning generated by notions of knowledge, beliefs, and intentions, 3) settled mindset conditioning meaning of experiences, 4) meaning and motivations generated in relationships contexts, and, 5) culturally rooted patterns of meaning.

The developed model does three important things. First, it helps with the reasonable hypothesizing about the experience of prostate cancer screening decision making among heterosexual West Indian Americans and African Americans. It helps to clarify to researchers the constructs which undergird the experience of PcA screening decision making process within the community these participants represent. Second, it also helps in the planning of future research such as structural equation modelling to better clarify the causal relationships between the constructs, particularly leading to prostate cancer screening behaviors among the men in this population. Third, the model helps to suggest to marital and family therapy academics and practitioners a clearer way of thinking about the appropriate types of interventions to enhance health screening behaviors in general and prostate cancer screening decision making and PcA screening behaviors more specifically as they serve heterosexual West Indian American and African American men men and their families. Finally the model helps to provide a more comprehensive understanding and overview of the experience of prostate cancer

screening decision making among heterosexual West Indian American and African American men and their partners.

### **Relationship to Theoretical Framework of Study**

Qualitative methods are useful for generating elements of a model of a phenomenon and very useful when investigating the perspectives of a subgroup of a population, in this instance African Americans and West Indian Americans with a lived experience. This study was useful in that it generated a collective feedback of a subgroup dealing with the phenomenon of the experience of prostate cancer screening decisions within the subgroup of the nation's population. Within the context of this dissertation the generated model seems to connect with the non-normative approach of symbolic interaction as it attempts to evaluate families through better understanding of meanings, interactions, cultural realities, and the utility of evolving meanings of diagnosed individuals and their partners and families in relationships. The qualitative approach attempted to probe into the participants lived experience which may have elements which are stable but are also adaptable as a constantly changing reality. Symbolic interaction seemed to offer a unique way of thinking and evaluating that fit well with the model. This is so because the constructs of the model are such as, uniquely acquired health conceptualizations, familial meaning generated by notions of knowledge, beliefs and intentions, religiosity/spirituality approaches to meaning of experiences, meaning and motivations generated in relationships contexts, and culturally rooted patterns of meaning are constantly changing constructs and interpreting them continually can be well informed by the theoretical perspective of symbolic interactionism.

The generated model also seemed to be compatible with symbolic interactionism in offering relevance for future research. For example, the concepts of identities, roles, interactions, meaning, and the concept of the self, seem conceptually related to the model's constructs such as culturally rooted patterns of meaning. It seems further that the model's apparent conceptual compatibility with symbolic interactionism ideas will be useful in further exploration of the model's constructs and their contribution to better understanding of the experience of PcA screening decision making. It will also enhance eclectic integration of concepts for systemic conceptualizations and therapeutic interventions to help in improving health screening behaviors within the African American and West Indian American population.

The generated model also suggests roles for familial relationships, settled mindsets, culturally rooted patterns of meaning, and familial meaning in aiding the planned health behaviors, health screening decisions and actual health screening behaviors (PSA testing & DREs) of the men in this population. Specifically the suggested hypothesis that familial relationships contribute to planned health behaviors, general health and prostate cancer screening decisions, and prostate cancer screening with the African American and West Indian American families.

### **Limitations of Study**

There are a several limitations of this study. First, the focus group approach itself had the potential to be influenced by one or two thought leaders that may have emerged during the process of discussion introducing the risk that the findings of the research may be somewhat biased. Efforts were made to limit or minimize the occurrence of

domination by thought leaders within the group. The researcher attempted to be respectful to participants and sought to include as many group members as possible in the group discussion and looked for ways to encourage group members to speak their own thoughts.

A second limitation of the study was that the topic of our inquiry was very sensitive and participants may have been unwilling to share some of their feelings about the questions that were asked. This could have been a limiting factor in the research and, therefore, may have influenced the data and emerging themes of the research. However, researcher utilized a variety of tools to avoid this phenomenon. This researcher attempted to be present early to engage in appropriate warming up, getting-to-know period before the focus group sessions began, and explaining ground rules to all focus group members sometimes individually and always collectively. The researcher also attempted to desensitize participants by speaking with them before focus group sessions. They were informed individually and collectively that only aggregate findings will be reported and that their honest participation and disclosure will be respected and appreciated.

A third limitation of this research was that even if consistency was determined from the data of multiple focus groups it is plausible that the results are representative of the reality of the participants but the findings may not be representative of the experience of all heterosexual West Indian American and African American men and their partners in the wider population. There is also the need for caution about the generalizability of the findings about experiences and behaviors across various respondents and participants (Fern, 2001). The additional difficulty with generalizability of the finding of these focus

groups also resulted from the fact that this research could only have been done in somewhat limited geographic locations and as such the findings are likely limited to the participants in the study and may not be generalizable to the entire universe of the sampled population. The benefit from the study will remain important in that the findings about the experience of prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners will be very helpful in generating hypotheses.

A fourth limitation of the focus groups was that they were conducted in a very artificial environment. Efforts were made to counteract potential biases and other difficulties related to the running of focus groups. Even though such efforts were made there was the possibility that the research may have been affected by the fact that it lacked the responses that participants may have given if they were in a “natural setting” and displaying their usual behaviors.

Future studies coming out of the proposed inquiry should then follow up this data collection with a quantitative phase during which findings are more widely applicable. In spite of these limitations of this research it still has the advantage of generating useful hypotheses that can be explored in future research. This research has effectively set the stage for and offer direction for the planned future research that pertains to the experience of prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners within the American population.

### **Utilization of Quantitative Research**

More research needs to be done to address the phenomenon of the experience of



prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners within the American population. There is also the need to better investigate and clarify the variables that work together to produce better and more functional prostate cancer screening decisions and behaviors among these men and their partners. To accomplish those research objectives it seems that it will be appropriate to engage in more quantitative methodologies. The quantitative work can be more targeted to some of the specific causal relationships that this model hypothesizes. The quantitative approach will be more targeted and may be less time consuming for the participants. Such a study will also be able to reach a greater number of participants thus making the findings more generalizable.

### **Conclusion**

The focus groups approach to this study resulted in a hypothesized model of possible causal relationships between constructs that may enhance the experience of prostate cancer screening decision making among heterosexual West Indian American and African American men and their partners. The model may suggest means of promoting prostate cancer screening behaviors among heterosexual West Indian American and African American men. The model hypothesizes about the prostate cancer screening decision making experience among these men and their partners. The hypothesized model suggests opportunities for quantitative research to confirm and elucidate the possible causal relationships between and within the theoretical framework of symbolic interactionism. As part of a wider Project C.H.A.NG.E research this model and additional quantitative information will help to enhance the richness of the

knowledge within the field of family therapy and will help to improve therapeutic approaches for heterosexual West Indian American and African men and their partners; an important sector of the American population.

## REFERENCES

- Abbott, R. R., Taylor, D.K., & Barber, K. A. (1998). Comparison of Prostate Knowledge of African American and Caucasian men: changes from [prescreening](#) baseline to post intervention. *Cancer Journal Science American*, 4, 175 – 177.
- Adams, B., Aranda, M. P., Kemp, B., & Takagi, K. (2002). Ethnic and gender differences in distress among Anglo American, African American, Japanese American, and Mexican American spousal caregivers of persons with dementia. *Journal of Clinical Geropsychology*, 8, 279–301.
- Addis, M. E., & Cohane, G. H. (2005). Social scientific paradigms of masculinity and their implications for research and practice in men’s mental health. *Journal of Clinical Psychology*, 61, 1–15.
- Addis, M. E., & Mahalik, J. (2003). Men, masculinity and the context of help seeking. *American Psychologist*, 58, 5–14.
- Almagor, M. & Ben-Porath, D. B. (2013). Functional dialectic Systems (FDS) treatment: Integrating family systems theory with dialectic thinking. *Journal of PsychotherapyIntegration*, 23(4), 397 – 405.
- American Cancer Society (2003). *Cancer Facts and Figures 2003*. Atlanta GA: American Cancer Society
- American Cancer Society. (2008). *Cancer Facts & Figures 2008*. Atlanta, GA: American Cancer Society.
- Andersen, B. L., & LeGrand, J. (1991). Body image for women: conceptualization, assessment, and a test of its importance to sexual dysfunction and medical illness. *The Journal of Sex Research*, 28, 457 – 477.
- Aspen Institute, Roundtable on Community Change. (2005). *Structural racism and youth development: Issues, challenges and implications*. Washington, DC: The Aspen Institute Printing Office.
- Aspinwall, L.G., & Taylor, S.E. (1992). Individual differences, coping and psychological adjustment: A longitudinal study of college adjustment and performance. *Journal of Personality and Social Psychology*, 63, 989-1003.
- Berge, B. L. (2007). *Qualitative Research Methods for the Social Sciences* (6<sup>th</sup> ed.). Boston, MA: Allyn & Bacon.
- Baade, P. D., Youlten, D. R. & Krnjackil, L. J. (2009). International epidemiology of prostate cancer: geographical distribution and secular trends. *Molecular Nutrition Food Research*, 53, 171 – 174.

- Balderson, N & Towell, T. (2003). The prevalence and predictors of psychological distress in men with prostate cancer who are seeking support. *British Journal of Health Psychology*, 8, 125 – 134.
- Banthia, R., Malcarne, V. L., Varni J. W., Ko, C. M., Sadler, G. R. & Greenbergs, H. L. (2003). The effects of dyadic strength and coping styles on psychological distress in couples faced with prostate cancer. *Journal of Behavioral Medicine* 26, 31–52.
- Bengston, V. L., Acock, A. C., Allen, K. R., Dilworth-Anderson, P., & Klein, D. M. (2005). Theory and theorizing in family research. In V.L. Bengston, A. C. Acock, K. R. Allen, P. Dilworth-Anderson, & D. M. Klein, (Eds.) *Sourcebook of Family Theory and Research*, Thousand Oaks, CA: SAGE Publications.
- Ben-Tovim, D. I., Dougherty, M. L., Stapleton, A., M. F., & Pinnock, C. B. (2002). Coping with prostate cancer: A quantitative analysis using a new instrument, the center for clinical excellence in urological research coping with cancer instrument. *Adult Urology*, 59, 383 - 388.
- Berg, C. A., & Upchurch, R. (2007). A social contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin*, 133, 920–954.
- Berg, C. A., Wiebe, D. J., Hayes, J., Butner, J., Bloor, L., Bradstreet, C., & Upchurch, R. (2008). Collaborative coping and daily mood in couples dealing with prostate cancer. *Psychology and Aging*, 23(3), 505 – 516.
- Berry, J.W. (1997). Immigration, acculturation, and adaptation. *Applied Psychology International Association of Applied Psychology*, 46(1), 5-34.
- Betancourt, H., & Flynn, P. M. (2009). The psychology of health: Physical health and the role of culture in behavior. In: Villarruel, F. A, Carlo G, Contreras Grau , J. M et al (Eds.), *Handbook of US Latino Psychology* (347-361). Thousand Oaks: Sage.
- Betancourt, H. & Lopez, S. R. (1993). The study of culture, ethnicity, and race in American psychology, *American Psychologist*, 48(6), 629 – 637.
- Blocker, D. E., Romocki, L. S., Thomas, K. B., Jones, B. L., Jackson, E. J., Reid, L. & Campbell, M. K. (2006). Knowledge, beliefs, and barriers associated with prostate cancer prevention and screening behaviors among African-American men. *Journal of the National Medical Association*, 98(8), 1286 – 1295.
- Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method*. Prentice Hall. Englewood Cliffs New Jersey, USA.
- Boman, E. K. O. & Walker, G. A. (2010). Predictors of men’s health care utilization. *Psychology of Men and Masculinity*, 11(2), 113 – 123.

- Bowen, M. (1976). Theory in the practice of psychotherapy. In *Family Therapy: Theory And Practice*, P. J. Guerin, ed. New York: Gardner Press.
- Boylorn, R.M. (2008). Lived Experience. In Given, L. M. (Ed.). *The Sage Encyclopedia of Qualitative research Methods*. DOI: <http://dx.doi.org/10.4135/9781412963909>
- Brantley, P.J., O’Hea, E.L., Jones, G., & Mehan, D.J. (2002). The influence of income level and ethnicity on coping strategies. *Journal of Psychopathology and Behavioral Assessment*, 24(1), 39 – 45.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. doi:10.1191/1478088706qp063oa
- Brawley, O. W. (2012). Prostate cancer epidemiology in the USA. *World Journal of Urology*, 30, 195 – 200.
- Brissette, I., Scheier, M.F., & Carver, C.S. (2002). The role of optimism in social Network development, coping, and psychological adjustment during a life transition. *Journal of Personality and Social Psychology*, 82(1), 102 - 111.
- Bronfenbrenner, U., & Evans, G. W. (2000). Developmental science in the 21st century:Emerging questions, theoretical models, research designs and empirical findings. *Social Development*, 9, 115–125.
- Burns, S. M. & Mahalik, J. R. (2008). Treatment type and emotional control as predictors of men’s self-assessed physical well-being following treatment for prostate cancer. *Psychology of men and Masculinity*. 9(2), 55-66.
- Cannon, C. A. Cavanaugh, J. C. (1998). Chronic illness in the context of marriage: a systems perspective of stress and coping in chronic obstructive pulmonary disease. *Families, Systems & Health*, 16(4), 401 – 418.
- Cantor, S. B., Volk, R. J., Cass, A. R., Gilani, J., & Spann, S. J. (2002). Psychological benefits of prostate cancer screening: the role of reassurance. *Health Expectations*, 5, 104 – 113.
- Castellblanch, R. & Abrahamson, D. J. (2003). What focus groups suggest about mental health parity policymaking. *Professional Psychology: Research and Practice*, 34(5), 540 – 547.
- Center, M. M., Jemal, A., Lortet-Tieulent, J., Warda, E., Ferlay, J., Brawley, O., & Bray F. (2012). International variation in prostate cancer incidence and mortality rates. *European Urology*, 1079 – 1092.
- Chappel, A. & Ziebland S. (2002). Prostate cancer: embodied experience and perceptions of masculinity. *Sociology of Health and Illness* Vol. 24. No. 6, 820 – 841.

- Charon, J. M. (2009). *Symbolic Interactionism An Introduction, An Interpretation, An Integration* (9<sup>th</sup> ed.). New York, NY: Prentice Hall.
- Chen, A.C., Macchia, R.J., Conway, F., Magai, C., Desai, M., & Neugut, A. I. (2004). Prostate-specific antigen, sex steroid hormones, and the insulin-like growth factor axis in U.S.-Born, Jamaican, and Haitian Black men: A pilot study, *Urology*, 64(3), 522 – 527.
- Chinegwundoh, F., Enver, M., Lee, A., Nargund, V., Oliver, T., & Ben-Shlomo, Y. (2006). Risk and presenting features of prostate cancer amongst African Caribbean, South Asian, and European men in North-east London. *British Journal of Urology International*. 98, 1216-1220.
- Chu, L. W., Ritchey, J., Devesa, S. S., Quraishi, S.M., Zhang, H., & Hsing A. W. (2011). Prostate cancer incidence rates in Africa. *Prostate Cancer*, 1 – 7.
- Chuang, S.S. & Gielen, U.P. (2009). Understanding immigrant families from around the world: introduction to special issue. *Journal of Family Psychology*, 23(3), 275 – 278.
- Coontz, S. (2000). Marriage Then and Now. *Phi Kappa Phi Journal*, 80, 16 – 20.
- Costa, P.T., Fagan, P. J., Piedmont, R.C., Ponticas, Y., & Wise, T. N. (1992). The five factor model of personality and sexual functioning in outpatient men and women. *Psychiatric Medicine*, 10, 199-215.
- Crawford, E. D. (2003). Epidemiology of prostate cancer. *Urology*, 62(6) 2 -12.
- Dale, W., Sartor, O., Davis, T., & Bennet, C. (1999). Understanding barriers to the early detection of prostate cancer among men of lower socioeconomic status. *The Prostate Journal* 1(4), 179-184.
- Daly, K. J. (2007). *Qualitative Methods for Family Studies & Human Development*. Los Angeles, CA: SAGE Publications.
- DeCuir-Gunby, J. T., Marshall, P. L. & McCulloch, A. W. (2011). Developing and using a codebook for the analysis of interview data: an example from professional development research project. *Field Methods*, 23(2),136 – 155.
- Dunkel-Schetter, C., Feinstein, L. G., Taylor, S. E., & Falke, R. L. (1992). Patterns of coping with cancer. *Health Psychology*, 11(2), 79 – 87.
- Efklides, A. (2008). Metacognition: defining its facets and levels of functioning in relation to self-regulation and co-regulation. *European Psychologist*, 13(4), 277-287.

- Fagundes, C. P., Berge, C. A., & Wiebe, D. J. (2012). Intrusion, avoidance, and daily negative affect among couples coping with prostate cancer: a dyadic investigation. *Journal of Family Psychology, 25*(2), 246 – 253.
- Feldman, L. B. & Pinsof, W. M. (1982). Problem maintenance in family systems: an integrative model. *Journal of Marital and Family Therapy, 295* – 308.
- Fergus, K. D. (2011). The rupture and repair of the couple's communal body with prostate cancer, *Family Systems and Health, 29*(2), 95 – 113.
- Ferlay, J., Shin H. R., Bray F., Forman, D., Mathers, C., Parkin, D. M. (2010). Cancer incidence and mortality worldwide: IARC CancerBase No. 10 Lyon, France: International Agency for Research on Cancer, 2010. Available from: <http://globocan.iarc.fr>. Accessed May 2011. IARC World Cancer Report 2008 IARC 2008.
- Fern, E. F. (2001). *Advanced Focus Group Research*. Thousand Oaks, CA: SAGE Publications.
- Fletcher, D., & Sarkar, M. (2013). Psychological resilience: a review and critique of definitions, concepts, and theory. *European Psychologist, 18*(1), 12 – 23.
- Frankel, M. R., Shapiro, M. F., Duan, N., Morton, S. C., Berry, S. H., Brown, J. A., Burnam, M/A., Cohn, S. E. Goldman, D. P., McCaffrey, D.F., Smith, S. M., St. Clair, P. A., Tebow, J. F., & Bozzette, S. A. (1999). National probability samples in studies of low prevalence diseases. Part II: Designing and implementing the HIV cost and services utilization study sample. *Health Services Research, 34*(5), Part 1.
- Friedman, D. B., Corwin, S. J., Dominick, G. M., & Rose, I. D. (2009). African American men's understanding and perceptions about prostate cancer: why multiple dimensions of health literacy are important in cancer communication. *Journal of Community Health, 34*, 449–460 DOI 10.1007/s10900-009-9167-3.
- Galdas, P. M., Cheater, F., & Marshall, P. (2005). Men and health help seeking behavior: Literature Review. *Journal of Advanced Nursing, 49*, 616– 623.
- Garfinkel, H. (1967). *Studies in ethnomethodology*. Englewood Cliffs, NJ: Prentice-Hall.
- Glaser, B. G. (1978). *Theoretical sensitivity: Advances in The Methodology of Grounded Theory*. Mill Valley, CA: The Sociology Press.
- Glaser, B. G., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL: Aldine.

- Goldenberg, I. & Goldenberg, H. (2008). Family Therapy. In Corsini, R J. and Wedding, W. (Eds.) *Current Psychotherapies* (8<sup>th</sup> Ed. P. 402 – 436). Belmont CA: Wadsworth.
- Graham-Steed, T., Uchio, E., Wells, C. K., Aslan, M., Ko, J., Concato, J. (2013). ‘Race’ and prostate cancer mortality in equal-access healthcare systems. *The American Journal of Medicine*, 126(12), 1084 – 1088.
- Gray, R.E., Fitch, M., Phillips, C., Labrecque, M., & Fergus K. (2000). To tell or not to tell: patterns of disclosure among men with prostate cancer. *Psycho-Oncology* 9, 273 –282.
- Green H.J., Wells D.J.N. & Laakso L. (2011). Coping in men with prostate cancer and their partners: a quantitative and qualitative study. *European Journal of Cancer Care* 20, 237 -247.
- Gronberg, H. (2003). Prostate cancer epidemiology. *Lancet*, 361, 859-864.
- Guzman, M., Santiago-Rivera, & Haase, R. (2005). Understanding Academic Attitudes and achievement in Mexican-origin youths: Ethnic identity, other-group orientation, and fatalism. *Cultural Diversity and Ethnic Minority Psychology*, 11 (1), 3 – 15.
- Haley, J. (1976). *Problem Solving Therapy*. San Francisco, CA: Josey-Bass.
- Hall, S. S. (2006). Marital meaning: exploring young adults’ belief system about marriage. *Journal of Family Issues*, 27(10), 1437 - 1458.
- Heiman, J. R. (2007). Orgasmic disorders in women. In Sandra R. Leiblum (Ed.). *Principles and Practice of Sex Therapy* (pp. 84 – 123). New York: the Guilford Press.
- Helgeson, V.S., Lepore, S. J., & Eton, D. T. (2006). Moderators of the benefits of Psychoeducational interventions for men with prostate cancer. *Health Psychology*, 25(3) 348 – 354.
- Herbert, T. B., & Cohen, S. (1993). Depression and immunity: A meta-analytic review. *Psychological Bulletin*, 113(3), 472 – 486.
- Herzberg, P.Y., Glaesmer, H. & Hoyer, J. (2006). Separating optimism and pessimism: A robust psychometric analysis of the revised life orientation test (LOT-R). *Psychological Assessment*, 18(4), 433 – 438.
- Hsing, A. W. (2001). Hormones and prostate cancer: what’s next? *Epidemiology Review*, 23, 42 – 58.



- Jaehee, Y. (2009). Cultural influences on the survivorship of families affected by childhood cancer: A case for using family systems theories. *Families, Systems, and Health*, 27(3), 228-236.
- Jeon, Y. (2004). The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Science*, 18, 249 – 256.
- Johnson, J.E., Lauver, D.R., & Nail, L.M., Process of coping with radiation therapy. *Journal of Consulting and Clinical Psychology*, 37(3), 358-364.
- Johnson, M. D., Cohan, C. L., Davila, J., Lawrence, E., Rogge, R. D., Karney, B. R., Sullivan, K. T., & Bradbury, T. N. (2005). Problem solving skills and affective expressions as predictors of change in marital satisfaction. *Journal of Consulting and Clinical Psychology*. 73, 13 – 27.
- Jussin, L., Suffin, S., Brown, R., Ley, J., & Kohlhepp, K. (1992). Understanding reactions to feedback by integrating ideas from symbolic interactionism and cognitive evaluation theory. *Journal of Personality and Social Psychology*, 62(3), 402 – 42.
- Kasinitz, P. (1992). *Caribbean New York: Black Immigrants and the Politics of Race*. Ithaca, N. Y: Cornell University Press.
- Kelly, S., Maynigo, P., Durham, J., & Wesley, K. (2013). African American communities and family systems: relevance and challenges. *Couple and Family Psychology Research and Practice*, 2(4), 264 – 277.
- Krueger, R. A. (1994). *Focus Groups A Practical Guide for Applied Research*. Thousand Oaks: SAGE Publications.
- Krueger, R. A. (2002). *Designing and Conducting Focus Group Interviews*. [Krueger@umn.edu](mailto:Krueger@umn.edu).
- Kudadjie-Gyamfi, E., Consedine, N. S., & Magai, C. (2006). On the importance of being ethnic: coping with the threat of prostate cancer in relation to prostate cancer screening. *Cultural Diversity and Ethnic Minority Psychology*, 12(3), 509 – 526.
- Lancastle, D. & Boivin, J. (2005). Dispositional optimism, trait anxiety, and coping: unique or shared Effects on biological response to fertility treatment. *Health Psychology*, 24(2), 171-178.
- Lane, J. M., & Addis, M. E. (2005). Male gender role conflict and patterns of help seeking in Costa Rica and the United States. *Psychology of Men & Masculinity*, 6, 155–168.

- LaRossa, R. & Reitzes, D. C. (1993). Symbolic interactionism and family studies. In P. G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.), *Sourcebook of Family Theories and Methods: A Contextual Approach* (pp. 135 – 163). New York: Plenum Press.
- Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Lease, S.H., Hampton, A.B., Fleming, K. M., Baggett, L.R., Montes, S.H., & Sawyer II, R.J. (2010). Masculinity and interpersonal competencies: Contrasting White and African American men. *Psychology of Men and Masculinity*, 11(3), 195- 207.
- Lee, C. & Owens, R. G. (2002). Issues for a psychology of men's health, *Journal of Health Psychology*, 7, 209 – 217.
- Leech, N. L. & Onwuegbuzie, A. J. (2008). Debriefing. In Lisa M. Given (Ed.). *The SAGE Encyclopedia of Qualitative Research Methods*,. Thousand Oaks CA: SAGE Publications USA.
- Leeds-Hurwitz, W. (2006). Social Theories: Social Constructionism and Symbolic Interactionism. In D. O. Braithwaith & L. A. Baxter (Eds.), *Engaging Theories in Family Communication Multiple Perspectives* (pp. 229 – 242). Thousand Oaks CA: Sage Publications Inc.
- Lepore, S. J., Helgeson, V.S., Elton, D. T., & Schulz, R. (2003). Improving quality of life in men with prostate cancer: a randomized control trial of group education interventions, *Health Psychology*, 22(5), 443- 452.
- Llic, D., Egdberts, K., McKenzie, J. E., Risbridger G., & Green, S. (2007). Informing men about prostate cancer screening: a randomized controlled trial of patient education materials. *Journal of General Internal Medicine*, 23(4), 466 – 471.
- Love, A. W., Scealy, M., Bloch, S., Duchesne, G., Couper, J., Macvean, M., Costello, A., Kissane, D.W. (2008). Psychosocial adjustment in newly diagnosed prostate cancer. *Australian and New Zealand Journal of Psychiatry*, 42, 423-429.
- Lubeck, D. P., Litwin, M. S., Henning J. M., Stoddard, M. L., Flanders, S. C., & Carrol, P. R. (1999). Changes in health-related quality of life in the first year after treatment for prostate cancer: results from CaPSURE. *Elsevier, Adult Urology*, 1, 180 – 186.
- MacQueen, K. M., McLellan, E., Kay, K. & Milstein, B. (1998). Codebook development for team-based qualitative research. *Cultural Anthropology Methods*, 10(2), 31 – 36.
- Madanes, C. (1981). *Strategic Family Therapy*. San Francisco, CA: Jossey-Bass.
- Madanes, C. (1984). *Behind the One-way Mirror*. San Francisco, CA: Jossey-Bass.

- Magnavita, J. J. (2013). Advancing clinical science using system theory as the framework for expanding family psychology with unified psychotherapy. *Couple and Family Psychotherapy Research and Practice*, 1(1), 1 – 13.
- Mahalik, J. R., Lagan, H., & Morrison, J. A. (2006). Health behaviors and masculinity in Kenyan and U.S. male college students. *Psychology of Men & Masculinity*, 7, 191–202.
- Mallick, S., Blanchet, P., & Multigner, L. (2005). Prostate cancer incidence in Guadeloupe, a French Caribbean Archipelago. *European Urology*, 47, 769 – 772.
- Marks, D. F. (1996). Health psychology in context. *Journal of Health Psychology*, 1, 7–21.
- McGouldrick M., & Giordano, J. (1996). Overview: ethnicity and family therapy. In *Ethnicity and Family Therapy*, Eds. Monica McGoldrick & Joe Giordano. New York: The Guilford Press.
- McLeod, J. (2010). *Case study research in counselling and psychotherapy*. London, England: Sage.
- McLeod, J., & Balamoutsou, S. (2006). A method for qualitative narrative analysis of psychotherapy transcripts. In J. Frommer & D. L. Rennie (Eds.), *Qualitative psychotherapy research: Methods and methodology* (2nd ed., pp. 128–152). Lengerich, Germany: Pabst Science.
- Mead, G. H. (1934/1959). *Mind, Self, and the Society: From the Standpoint of a Social Behaviorist*. Chicago, IL: The University of Chicago Press.
- Mengel, M. B., Connis, R. T., Gordon, M. J., & Taylor, T. R. (1998). The relationship of family dynamics and social support to personal, psychological, and social functioning in diabetic patients on the insulin pump. *Family Systems Medicine*, 6(3), 317 – 334.
- Meyer, J. F., Talbot, A. P., & Ranalli, C. (2007). Why older adults make more immediate treatment decisions about cancer than younger adults. *Psychology and Aging*, 22(3), 505-524.
- Miller J. F. (2000) *Coping with Chronic Illness: Overcoming Powerlessness*, 3<sup>rd</sup> ed. F.A. Davis, Philadelphia, PA, USA.
- Minuchin, S. (1974). *Families and Family Therapy*. Cambridge, MA:Harvard University Press.
- Mirgain, S. A., & Cordova, J. V. (2007). Emotion skills and mental health: the association between observed and self reported emotion skills, intimacy, and marital satisfaction. *Journal of Social and Clinical Psychology*, 26, 983 – 1009.

- Moreno, M. A., Egan, K. G., & Brockman, L. (2011). Development of a research codebook for use in evaluating social networking site profiles. *Journal of Adolescent Health, 49*, 29-35.
- Morgan, D. L. (1989). *Focus Groups as Qualitative Research*. Newbury Park CA: Sage Publications.
- Moul, J.W. (2000). Targeted screening for prostate cancer in African-American men. *Prostate cancer and Prostatic Diseases, 3*, 248 – 255.
- Murphy, E.J., & Mahalingam, R. (2006). Perceived congruence between expectations and outcomes: implications for mental health among Caribbean Immigrants. *American Journal of Orthopsychiatry, 76*(1), 120-127.
- Myers, R.E., Chodak, G.W., Wolf, T.A., Burgh, D. Y., McGrory, G. T., Marcus, S.M., Diehl, J. A., & Williams, M. (1999). Adherence by African-American men to prostate cancer education and early detection. *American Cancer Society, 86*(1), 88 – 104.
- Nock, S. L. (1998). *Marriage in Men's Lives*. New York: Oxford University Press.
- Ocho, O. N. & Green, J. (2013). Perception of prostate cancer screening services among men in Trinidad and Tobago. *Springer Science and Business Media New York, Sex Research and Social Policy, 10*, 186 – 192.
- Olson, D. H. (2000). Circumplex model of marital and family systems. *Journal of Family Therapy, 22*, 144-167.
- Oppenheimer, V. K. (1994). Women's rising employment and the fate of the family in industrialized societies. *Population Development Review, 20*, 293 – 342.
- Pedersen, V. H., Armes, J., & Ream, E. (2012). Perceptions of prostate cancer in Black African and Black Caribbean men: a systematic review of the literature. *Psycho-Oncology, 21*, 457 – 468.
- Pendleton, J., Hopkins, C., Anai, S., Nakamura, K., Chang, M. Grissett, A. & Rosser, C.J. (2008). Prostate cancer knowledge and screening attitudes of inner-city men. *Journal of Cancer Education, 23*, 172 – 179.
- Perez, M. A., Skinner, E. C. & Meyerowitz, B.E. (2002). Sexuality and intimacy following radical prostatectomy: Patient and partner perspectives. *Health Psychology, 27*(3), 288 – 293.
- Peters, N. & Armstrong, K. (2005). Racial differences in prostate cancer treatment outcomes. *Cancer Nursing, 28*(2), 108 – 118.

- Platz E. A, Giovannucci E. Prostate cancer. In: Schottenfeld D, Fraumeni J. F, editors. *Cancer Epidemiology and Prevention*. New York, NY: Oxford University Press; 2006. p. 1128 – 50.
- Powell, I. J. Banerjee, M., Bianco, F. J., Wood, D. P., Dey, J. Lai, Z., Heath, M., & Pontes, E. (2004). The effect of race/ethnicity on prostate cancer treatment outcome is conditional: A review of Wayne State University Data. *The Journal of Urology*, 171, 1508 – 1512.
- Ramisch, J. (2012) Marriage and family therapists working with couples who have children with Autism. *Journal of Marital and Family Therapy*, 38(2), 305 – 316.
- Redfield, R., Linton, R., & Herskovits, M. (1936). Memorandum on the study of acculturation, *American Anthropologist*, 38, 149 – 152.
- Revenson, T. A. (1994). Social Support and Marital coping with chronic illness. *Annals of Behavioral Medicine*, 16, 122 – 130.
- Revenson, T. A. (2003). Scenes from a marriage: Examining support, coping, and gender, within the context of chronic illness. In J. Suls & K. A. Wallston (Eds.), *Social Psychological Foundations of Health and Illness*. Malden MA: Blackwell Publishing.
- Robinson S. B, Ashley, M., Haynes M. A. (1996). Attitudes of African Americans regarding prostate cancer clinical trials. *Journal of Community Health*, 21(2), 77 – 87.
- Rohner, R. P. (1984). Toward a conception of culture for cross-cultural psychology. *Journal of Cross-Cultural Psychology*, 15, 111-138.
- Sandstrom, K. L., Martin, D. D., & Fine, G. A. (2001). Symbolic interactionism and the end of the century. In G. Ritzer & B. Smart. (Eds.) *Handbook of Social Theory* (pp. 217 – 231). Thousand Oaks, CA: Sage.
- Schneider, A. (2011). Symbolic interactionism: from gestalt to cybernetics. In Derek Chadee(Ed.) *Theories in Social Psychology*, Malden, MA: Wiley-Blackwell.
- Schroder, F. H. & Robol, M. J. (2012). Prostate Cancer epidemic in sight? *European Urology*, 61, 1093 – 1096.
- Schwartz, R. C. (1995). *Internal Family Systems Therapy*. New York: The Guilford Press.
- Searight, H. R. & Young, R. (1994). Qualitative research and family systems medicine: a natural fit. *Family Systems Medicine*, 12(2), 117 – 131.

- Shelton, J. B., Barocas, D. A., Conway, F., Hart, K., Nelson, K., Richstone, L., Gonzalez, R. R., Raman, J. D., & Scherr, D. (2004). Prostate-specific antigen screening in a high-risk population: lessons from the community and how they relate to large scale population based studies. *Journal of Urology*, 65(5) 931 – 936.
- Shirley, S.E., Escoffery, C. T., Sargeant, L.A., Tulloch, T. (2002). Clinicopathological features of prostate cancer in Jamaican men. *British Journal of Urology International*, 89, 390 – 395.
- Sieverding, M., Mattered, U., Ciccarello, L. (2010). What role do social norms play in the context of men's cancer screening and behavior? Application of the extended theory of planned behavior. *Health Psychology*, 20(1), 72 – 81.
- Silverman, D. (1998). *Harvey Sacks: Social science and conversation analysis*. New York, NY: Oxford University Press.
- Spangler, J. G. & Reid, J. C. (2010). Environmental manganese and cancer mortality rates by county in North Carolina: an ecological study. *Biological Trace Elements Research; Humana Press*, 133, 128 – 135.
- Sperry, L. (2010). Treating patients with heart disease: the impact of individual and family dynamics. *The Family Journal: Counseling and Therapy for Couples and Families* 19(1) 96-100.
- Smith, D. S., Bullock A.D, Catalona W.J., & Herschan J.D. (1996). Racial Differences in a prostate cancer screening study. *Journal of Urology*, 156, 366 – 369.
- Smith, D. S., Bullock A.D., & Catalona W.J. (1997). Racial differences in operating characteristics of prostate cancer, *Journal of Urology*, 158, 1861-1866.
- Spanier, G. B. (1976). Measuring dyadic adjustment: new scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and Family* 38, 15–27.
- Stanford, J.L., Feng, Z., Hamilton, A.S., Gilliland, F.D., Stephenson, R.A., & Eley, J.W. (2000). Urinary and sexual function after radical prostatectomy for clinically localized prostate cancer: the prostate cancer outcomes study. *Journal of the American Medical Association*, 283, 354 – 360.
- Strauss, A. & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory (2nd. Ed.)*. Thousand Oaks, CA: Sage.
- Sue, D. W., & Sue, D. (1990). *Counseling the culturally different: Theory and practice*. New York: Wiley.
- Taylor, S. E. (1983). Adjustment to threatening events, a theory of cognitive adaptation. *American Psychologist*, 1161-1173.

- Taylor, S.E., & Brown, J.D. (1988). Illusion and well-being: a social psychological perspective on mental health. *Psychological Bulletin* 103(2), 193 – 210.
- Taylor, S. E., Kemery, M.E., Aspinwall, L.G., Schneider, S.G., Rodriguez, R., & Herbert. M. (1992). Optimism, coping, psychological distress, and high risk sexual behavior among men at risk for acquired immunodeficiency syndrome (AIDS). *Journal of Personality and Social Psychology*, 63(3), 460-473.
- Thoits, P. A. (1986). Social support as coping assistance. *Journal of Consulting and Clinical Psychology*, 54, 416–423.
- Thompson, I. M., Tangen, C. M., Tolcher, A., Crawford, E.D., Eisenberger, M., & Moinpour, C.M. (2001). Association of African-American ethnic background with survival in men with Metastatic prostate cancer. *Journal of The National Cancer Institute*, 93(3), 219 – 225.
- Thompson, E. H., & Pleck, J. H. (1995). Masculine ideologies: A review of research instrumentation on men and masculinities. In R. F. Levant & W. S. Pollack (Eds.), *A new psychology of men* (pp. 129–163), New York: Basic Books.
- Triandis, H., Lambert, W., Berry, J., Lonner, W., Heron, A., Brislin. R., & Draguns. J. (Eds.). (1980). *Handbook Of cross-Cultural Psychology: Vol.s. 1-6*. Boston: Allyn & Bacon.
- Tudge, J. R. H., Mokra, I., Hatfield, B. E., & Karnik, R. B. (2009). Uses and misuse of Bronfenbrenner's bioecological theory of human development. *Journal of Family Theory and Review*, 1, 198–210.
- U.S. Cancer Statistics Working Group. [United States Cancer Statistics: 1999–2010 Incidence and Mortality Web-based Report](#). Atlanta (GA): Department of Health and Human Services, Centers for Disease Control and Prevention, and National Cancer Institute; 2013. Available at: <http://www.cdc.gov/uscs>.
- Vijayakumar S et al. (1998). Prostate specific antigen levels are higher in African Americans than in White patients in a multicenter registration study: results of RTOG 94-12. *International Journal of Radiation, Oncology, Biology, and Physiology*, 40, 17 - 25.
- Volk, R. J., Canter, S.B., Cass, A.R., Spann, S. J., Weller, S.C., & Krahn. M.D. (2004). Preferences of husbands and wives for outcomes of prostate cancer screening and treatment. *Journal of General Internal Medicine*, 19, 339-348.
- Waite, L. J. & Gallagher, M. (2000). *The Case for Marriage: Why Married People are Happier, Healthier, and better off financially*. New York: Doubleday.

- Waldrop, D., Lightsey, O.R., Ethington, C.A., Woemmel, C.A., & Coke, A. (2001). Self efficacy, Optimism, health competence and recovery from orthopedic surgery. *Journal of Counseling Psychology*, 48(2), 233 – 238.
- Waters, M. C. (1998). *Black Identities West Indian Immigrant Dreams And American Realities*. Cambridge Massachusetts: Harvard University Press.
- Weston R. E., Weston, P. J., Futterman, R.F., Lepore, S.J., Carolina, D.S., Pinto, J. T., Michele, A. L., Thomas, R. I., Cardwell, J. J., Gordon, A. P. (2007). Effectiveness of a modified computer assisted instructional tool in the dissemination of prostate cancer information to men of African American descent through Black Churches. *Journal of African American Studies*, 11, 140-156.
- White, J. M., & Klein, D. M. (2008). *Family Theories*, (3<sup>rd</sup> ed). Los Angeles, CA: SAGE Publications.
- Wilkinson, S. (2004). Focus group research. In D. Silverman (Ed.). *Qualitative research: Theory, method, and practice* (pp. 177 – 199). London: Sage.
- Williams-Piehot, P. A. McCormack, L. A., Treiman, K., & Bann, C. M. (2008). Health information styles among participants in a prostate cancer screening informed decision making intervention. *Health Education Research*, 23(2), 440 – 453.
- Williams, D.R., Haile, R., Gonzalez, H.M., Neighbors, H., Baser, R., & Jackson, J. (2007). The mental health of Black Caribbean Immigrants: Results from the National survey of American Life. *American Journal of Public Health*, 97(1), 52-59.
- Williams, D. R.; Wilson, C. M. (2004). Aging; Minority Groups; Racial and Ethnic Differences; Socioeconomic Status; Adulthood (18 yrs & older); Aged (65 yrs & older). In Binstock, R. H. & George, L. K. (Eds.), *Handbook of Aging and the Social Sciences* (5th ed.).(pp.160-178). San Diego, CA: Academic Press,
- Woods, V.D., Montgomery, S. B., Herring, P., Gardner, R.W., & Stokols, D. (2006). Social ecological predictors of Prostate-Specific Antigen blood test and Digital Rectal Examination in Black American men. *Journal of the National Medical Association*, 98(4), 492–504.
- Wray, R. J., McCklure, S., Vijaykumar, S., Smith, C., Ivy, A., Jupka, K., Hess, R. (2009). Changing Conversation about prostate cancer among African American: the results of formative Research. *Ethnicity and Health*, 14(1), 27 – 43.
- Wyatt, P. K. (1999). Conceiving couple commitment, choice, promise and fulfillment. In J. M. Adams & W. H. Jones (Eds). *Handbook of Interpersonal Commitment and Relationship Stability* (pp. 53 – 72). New York: Plenum Press.
- Yin, R. K. (2003). *Case Study Research* (3<sup>rd</sup> Ed.). Thousand Oaks, CA: Sage



Zhang W et al. (2000). Inflammatory infiltrate (prostatitis) in whole-mounted radical prostatectomy specimens from black and white patients is not an etiology for racial difference prostate specific antigen. *Journal of Urology*; 163, 131 - 136.

APPENDIX A

DEMOGRAPHIC QUESTIONNAIRE



LOMA LINDA UNIVERSITY

**Project C.H.A.N.G.E – Changing Health for Adult Men with New and Great Experiences**

*Demographic Questionnaire*

Age: 20 – 25 \_\_\_\_, 26 – 30 \_\_\_\_, 31 – 35 \_\_\_\_, 36 – 40 \_\_\_\_, 41 -50 \_\_\_\_, 51 & older \_\_\_\_

Sex: Male Female

What is your current Marital Status:

- Never Married
- Married
- In cohabiting relationship
- Divorced/Separated
- Widowed

Number of Years Married to Current Spouse: \_\_\_\_\_

**On a scale of 1 to 7, where 1 is extremely dissatisfied and 7 extremely satisfied, Kindly answer the following three Questions:**

How satisfied are you with your marriage?

- 1) Extremely Dissatisfied, 2) very dissatisfied, 3) Somewhat Dissatisfied, 4) Mixed
- 5) Somewhat Satisfied, 6) Very Satisfied, 7) Extremely Satisfied.

How satisfied are you with your husband/wife as a spouse?

- 1) Extremely Dissatisfied, 2) very dissatisfied, 3) Somewhat Dissatisfied, 4) Mixed
- 5) Somewhat Satisfied, 6) Very Satisfied, 7) Extremely Satisfied.

How satisfied are you with your relationship with your husband/wife/Partner?

- 1) Extremely Dissatisfied, 2) very dissatisfied, 3) Somewhat Dissatisfied, 4) Mixed
- 5) Somewhat Satisfied, 6) Very Satisfied, 7) Extremely Satisfied.

Which of the following best describes your Ethnicity?

African American: \_\_\_\_\_

Caribbean American: \_\_\_\_\_

Other (Please Specify): \_\_\_\_\_

**Generational Status**

Length of Stay ( in years) In the USA

Are you currently employed? Circle One. YES NO

Are you Employed (Circle One): Full Time or Part Time

Do You Currently Have Health Insurance? Circle One. YES NO

Has any member of your immediate family ever been diagnosed with prostate cancer?  
YES NO

Have you ever been diagnosed with prostate cancer by a medical professional?

Length of Time in years since Diagnosis? Circle 1 (1-4); (5 – 8); (9 – 12); ( over 12)

**Educational Level:**

How many years of formal education Completed? \_\_\_\_\_

High School: 12 Years

Associated Degree: 14 years

College Degree: 16 Years

Masters Degree: 18 Years

Beyond Masters Degree: over 18 years

**Income Level:** \$ 20, 000 to 30, 000; 31, 000 to 40,000; 41, 000 to 50, 000, 51, 000 to 60,000, 61,00 to 75, 000; Above \$75,000

Have you ever had a Digital Rectal Examination for Prostate Cancer? YES NO

Have you had a rectal Examination for Prostate Cancer in the past 12 months? YES  
NO

Have you ever had a blood test for prostate cancer? YES NO

Have you had a blood test for prostate cancer in the past 12 months? YES NO

Have you ever been diagnosed with prostate cancer? YES NO

**APPENDIX B**  
**FOCUS GROUP QUESTIONS**



LOMA LINDA UNIVERSITY

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**Project C.H.A.N.G.E – Changing Health for Adult Men with New and  
Great Experiences  
Focus Group Questions**

**Introduction (describe study aims, purpose); do verbal consent (go over the consent form, including procedures, ask again about recording); talk about ground rules: no wrong opinions, everyone has a right to their thoughts without critique by others, let people speak, do not share confidences**

**Ice-breaker Questions**

1) If you could choose 3 adjectives to describe yourself, what words would you choose?

**Main Questions**

- 2) What does “health” mean to you as a male? Give us some examples.
  - a. To your partner/ your family
  - b. How does stress fit?
  
- 3) What are some of the “highs” and the “lows” of your lives?
  - a. Relationships
  - b. Separation from country
  - c. Role as a male in society
  
- 4) What are some of the issues that are important to you in terms of men’s health?
  - a. Prostate cancer
  - b. Do you ever talk about it? – With your partner, other men like you?
  - c. Do you know anyone who has had or has prostate cancer- who – what were their experiences?

- 5) What role do you play in the maintenance of your health?
  - a. Particularly in prostate health issues?
  - b. General health screening issues?
  
- 6) How about prostate cancer screening?
  - a. Have you considered getting such testing done?
  - b. Why /why not?
  - c. Is it important to your family? Was it discussed in the family? Was it discussed with any other men like you? Did you discuss details about it i.e. digital rectal examinations and prostate specific antigen tests (PSA tests); why and why not?
  - d. Have you ever discussed these issues with your doctor? Did you think they were important enough to discuss them with your doctor?
  - e. What are the positive sides and what the negative sides of testing (benefits)?
  - f. How about if you found out you have cancer—what would you do?
  
- 7) Can you describe for me how men talk about prostate cancer?
  - a. Do men think there are things they can do to prevent getting prostate cancer
  - b. What should one do to reduce risk of prostate cancer
  - c. How about stress, diet, exercise? Tell me a little about those things.
  - d. What do men fear the most when they think about prostate cancer?
  
- 8) Tell me what you heard how men may deal with a diagnosis of prostate cancer?
  - a. Tell me about how your family may deal with a diagnosis of prostate cancer? Tell me about how you talk about it...tell me about how it may affect your relationship...is it possible that you got/may get closer as a result of the diagnosis?
  
- 9) How might this affect the way men feel about their own manhood or masculinity?
  - a. Tell me how so?
  - b. How about sex/closeness?
  
- 10) Do you feel that beliefs men hold about life and health in general affected the way you deal with issues like prostate cancer screening and the diagnosis of prostate cancer?
  - a. Tell me more about your beliefs. Do you think that some things must happen a certain way no matter what? Do you think there is nothing a person can do to avoid certain things? Some people call that fatalism or fate, do you believe in that? Tell me some more.

- b. How about God/ a higher power?
  - c. Fate? Personal Responsibility
- 11) Tell me a little about your family communication. Do you discuss things in general a lot?
- a. Do you talk about how you look at health/illness?
  - b. Do you discuss health care decisions as a family/couple?
  - c. Who would be the first person you would consider sharing a diagnosis of prostate cancer with? – How soon?
  - d. Do you discuss prostate cancer screening decisions as a couple/family?
- 12) What may/does having a diagnosis of prostate cancer mean to people in general?
- a. Men?
  - b. To you an individual
  - c. To you as a couple?
- 13) How should we educate black men about health in general
- a. How about stress
  - b. How about prostate cancer and the benefits of early detection?
- 14) Where do you think men get their beliefs about prostate cancer from?

### **Exit Questions**

- 15) Of all the things that we discussed today as they relate to you, your family relationship, prostate cancer screening behaviors, prostate cancer diagnosis, fatalism, and spirituality, what would you say is the most important?
- 16) If you had all the resources you needed and could help men with this issue (prostate cancer—how would you go about helping other men with this?

**Closing comments:** - Thank you. Express appreciation for participant’s time, trust, honesty— in other words, their participation in the focus group. Remind them of ground rules regarding not sharing of confidences shared during (and after) the group discussions.

We will have groups with men and their female partners (separate); we will have groups with younger (<40) men and men 41+; we also try to have a group of men with a history of prostate cancer.

Questions will be modified accordingly but always along the outline above. I.e. How concerned are you about your spouse having p cancer? If your spouse were to be diagnosed – what do you see as your role in helping him? How would your spouse having

p cancer affect you – would be different from him having a different kind of cancer?  
What are the possible causes of prostate cancer? (Probe: STI's – myths—what have you heard). Modifications: For men with prostate cancer: add Q. re treatment experiences and alternative treatments

## APPENDIX C

### EXPLANATION OF STUDY



LOMA LINDA UNIVERSITY

### **Experience of Prostate Cancer Screening Decision Making in Heterosexual Caribbean American Men and their Partners Questions**

#### **Explanation of Study**

We are inviting you to participate in a study to examine how men like you think about and experience their health including how they come to make prostate cancer screening decisions and how their partners fit into this. The study will use personal and group interviews and surveys to capture your thoughts and experiences.

We will ask you a set of questions to accomplish this goal. Each person will be asked to complete a short survey about themselves and some thoughts about their perceived health risks and attitudes. In the one-on one and group discussions we ask that you allow us to audio tape your responses. We will then transcribe the audio recordings verbatim and remove all identifying information. Please feel free to answer the questions to the best of your ability; there are no wrong answers, only your thoughts and experiences. Your honesty and candor in answering these questions will greatly help us in the field of men's health to better understand how men value health and come to decisions about health risks and prevention.

Before you participate we are asking you to fill out a consent form which explains the study in some additional detail. By signing the consent form you agree to participate in our study and allow us to use the information you provided with that of other men like you to better understand how men arrive at prevention decisions about their health.

We want you to know, that while your responses are confidential and we will do all we can to de-identify your responses, anytime when you share thoughts in group settings there is a small risk of breach of confidentiality. However, we will do all we can to keep your responses confidential and will never identify any responses as your own. All results will be analyzed and reported in conjunction with that of other men to protect everyone's privacy.



Susanne Montgomery, MPH, PhD  
*Professor of Social Policy and Director of Research*  
Behavioral Health Institute  
Loma Linda University  
*phone* 909-558-9586 (ext: 89586)  
*fax* 909-558-9593 (ext: 89593)

Horatius Gittens, M.A.  
Loma Linda University  
PhD © June 2014 Expected Graduation Date.

## APPENDIX D

### INFORMED CONSENT FORM



LOMA LINDA UNIVERSITY

### INFORMED CONSENT FOR PROJECT C.H.A.N.G. E – CHANGING HEALTH FOR ADULT MEN WITH NEW AND GREAT EXPERIENCES

We are inviting you to participate in a study to examine how men and their female partners think about health, the role of stress in health, and how they come to make prostate cancer screening decisions. The study will use personal, group interviews and surveys to capture your thoughts and experiences.

We will ask you a set of questions, first each person will be asked to complete a very brief survey that helps us understand a little more about who you are. In the one-on-one and group discussions we ask that you allow us to audio tape your responses. We will then transcribe the audio recordings verbatim and remove all identifying information. Once the transcription is completed we will delete the recordings. Please feel free to answer the questions to the best of your ability; there are no wrong answers, only your thoughts and experiences. Your honesty and candor in answering these questions will greatly help us in the field of men's health to better understand how men value health and come to decisions about health risks and prevention.

#### **Risks and Benefits of Study Participation**

By participating in this study there are no direct benefits to you. However, your answers will help us better understand men's needs related to health. Learning more about your thoughts, knowledge, beliefs and experiences can help us to plan appropriate family and couple interventions that can aid in enhanced screening decisions, early detection and diagnosis, and early interventions and treatment for prostate cancer. We also hope that you will find the group discussions useful and fun, as talking about this may enrich your own experiences. While we anticipate minimal risks related to this study, some of the questions we ask may feel private and some may cause strong emotions. If you feel that you need to talk with someone as a follow up you will be given a list of services. Please know that at any time during the group interview, you can refuse to answer questions or end your participation in the group. Also, if at some time you have concerns you may ask me to turn off the tape recorder at any time.

**Confidentiality**

Participation in any of the study activities is voluntary and confidential. If other participants are present, they will be asked not to share any information shared by other participants outside of the group. The audio recordings will be transcribed and the transcriber will remove all identifying information so that your responses will not be traced back to you.

As a small token of appreciation for your time and thoughtful contribution to the study you will receive a small monetary gift at the end of the data collection

You may ask any questions you have now, or if you have questions later, feel free to call Dr. Montgomery at 909-558-8745. If you wish to contact a third party not associated with this study regarding any question or complaint you may have about the study, you may contact the Office of Sponsored Research, Loma Linda University, Loma Linda, CA 92350, phone (909)558-4531.

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

**Statement of Consent**

I have read the consent form and have listened to the verbal explanation given by the investigator. My questions concerning the study have been answered to my satisfaction. I hereby give voluntary consent to participate in this study. Signing this consent form does not waive my rights nor does it release the investigator's institution or sponsors from their responsibilities.

Signature of Participant: \_\_\_\_\_  
\_\_\_\_\_

Date:

Printed Name: \_\_\_\_\_

I have reviewed the contents of this form with the person signing above. I have explained the potential risks and benefits of this study.

Signature of Investigator: \_\_\_\_\_  
\_\_\_\_\_

Date:

Printed Name: \_\_\_\_\_

**APPENDIX E**  
**DISSERTATION EXAMPLES OF MEMORANDA**

**March 9<sup>th</sup> 2014** (African American Men)

Health seemed to be well conceptualized during the discussions generated during this focus group. Health seemed to be thoroughly conceptualized during the first focus group session. Health conceptualization was often stated in relationship to family mostly or drawn into relational terms that pertained to person and /or families. This seems important. Health is probably not an individualistic item in the minds of these participants.

Some men seemed to claim knowledge about prostate cancer but their actual knowledge appeared inaccurate.

Memo: Men seemed to be trying to clarify their understanding of their own health and the issues that affect their achieving and maintaining health.

**March 11<sup>th</sup> 2014** – Memo: During transcription and open coding memo I wrote : “Here the diagnosis of PcA seemed to resonate differently among the men from the very fearful and daunting on the one hand and to the point of non-serious on the other hand”)

Also - Sense of masculinity seemed to be one of the driving concerns surrounding PcA diagnosis.

During the review of transcript I noticed and wrote:

“(Memo: here the issue of masculinity, longevity and prostate cancer intersect again and it seems to consistently show up. Following also is the dialogue about sexuality and masculinity).

Memo: the female spouses surfaced as being the person contributing to male health maintenance)

(Memo: Here the issue about taking about health within the wider African American communication about health is called into question. This to me was an interesting take on the whole thing/discussion)

Tress did not seem to be addressed thoroughly during this first grou. . .stress was discussed as an external thing that attacked individuals and families.

Families and jobs were introduced as sources of stress.

**March 16<sup>th</sup> 2014** (African American Men)

A different concept of health than was previously discussed was introduced during this session; it was health conceptualized as engagement with medical doctors. However this group had very diverse opinions about many of the issues discussed. There seemed to have been a willingness of the younger men of the group to be influenced by the older men of the group. A very cordial attitude dominated during the session.

The younger men of this group (under 40-years-old) seemed motivated but expressed much less knowledge and previous interest in prostate cancer screening. During session these very men chorus a response of being willing to engage in screening as soon as they became 40-years-old. They seemed to have been grateful for the expressions of the need for this behavior and the encouragement of older men to participate in this behavior.

During review of transcript I realized that based on participant's comments (Memo: Participant is a heavier set African American and I got to thinking that weight probably crosses over in its effect on people's health ideas in a very general way).

I question if visiting doctors and other medical providers (Memo: visiting the doctor among this group of younger African Americans – a lack of motivation to see the doctor. What really was this I wondered.)

(Memo: the phenomenon of trust of doctors in a manner that seemed to indicate a lack of knowledge about what a doctor's role in men's health should be. It seems that this has terms of doctors' communication and in terms of doctor's competence in carrying out the DRE screening procedure surfaces in some of these men's discussions).

(Memo: a good mix of young and old men seemed to be suggesting that it would be a helpful measure in forming groups to provide general health and prostate cancer education to African American Men).

(Memo: the stress relieving nature of prostate cancer screening – including biopsy, and it was emphasized as useful in the stress relieving aspect of health management).

(Memo: here again medical competence has become an issue in dealing with the prostate cancer issues and all issues related to prostate cancer screening – including biopsy).

(Memo: commination among family members seemed to emphasize the importance of support for the screening behaviors. The communication from the female spouse of support for the men participating in screening. This was emphasized in this group. This was an interesting phenomenon.

### **March 16<sup>th</sup> 2014** (African American Couples)

Couples appeared very engaged during the session. They were apparently very free in their disclosure and the group soon developed camaraderie as session continued. Moderator occasionally had to attempt to move session along.

During session a recently diagnosed participant was very willing to share his experience related to PcA diagnosis and treatment. He shared multiple aspects of his experience. This sharing may have been motivational in encouraging other members to share their own unique experiences.

At some point in session Memo: (At this point I felt that the couples had saturated the ideas forthcoming about their understanding of health. They had begun repeating the same things. I felt a need to move session along)

(Memo: the general trend of thought of this line of responses seems to be the proactivity in health management, gaining knowledge and doing the medically appropriate things such as going to doctors and complying with medication and other forms of medical treatment)

(Memo: wife's role and success in attending to children's health issues was surfacing often in the discussion with the men)

Memo: Men's unwillingness to talk among themselves about PcA. Here the unwillingness of men to talk about prostate cancer surfaces in a very obvious way).

(Memo- Communication is addressed in advanced of the question of family communication)

Memo: the maintenance and preservation of masculinity seemed to be one of the issues that men aspired to maintain as reflected in their comments during sessions.

Memo: the conceptualization of masculinity seemed to be narrowly linked to sexuality as was expressed in the concerns of some men. Remarkably women saw masculinity as a broader and more inclusive concept.

### **March 30<sup>th</sup> 2014** (West Indian Men)

During this session I started out being eager to observe differences that may show up as contrasted to the African American groups. Session proceeded and concluded and I cannot say that I observed anything that was significant and different. I was conscious that I seemed to easily understand references to issues as they discussed culturally based experiences regarding their experiences with doctors and their evaluation of those experiences. It may be fair to say that my connection to the group was easier but I also had a good connection with participants of the previous groups.

Health as a shared responsibility for man and spouse was expressed but that seemed to be an issue that was mainly focused on the children and spouses in the family. men seemed to expressed more reluctance for attentiveness to their own health even as it was considered a shared responsibility. This was an interesting observation.

Prostate cancer as a threat to manhood and sexuality was expressed as a very concerning issues for the men in the group. They expressed fear of PcA as a threat to their masculinity. It seemed to me that the fear featured as a part of the prostate cancer screening decision making experience with these men.

There was a PcA survivor in this group and it was very evident that he also was very willing and eager to share his experiences. He seemed to have been well received by other group members who were very supportive as evidenced in their encouragement of participant as his sharing became emotional and tearful at times.

The participants seemed to be persuaded about the need for prostate cancer screening as something they needed to participate in and expressions were made by some other participants that they would be engaged in screening behaviors consistently at least annually.

As I reflected on this session and the sessions before I became aware of the power of the individual experience/testimony as a motivating tool to encourage men/families to engage in the prostate cancer screening decisions. The experience of prostate cancer screening decision making among these men (and probably similar men) and their partners may be significantly influenced by the experience of those who disclosed their own experiences. I further wondered about the effects of diagnosed couples sharing because I remembered during my reflections that in the African American couples group the sharing of the experience was done by the diagnosed man and his partner. It was a serendipitous discovery that I made during these sessions. Maybe there is much more to be learned during these sessions. I will wait to see if there are other diagnosed people in future sessions.

Memo: the holistic aspect of health seemed to dominate this group's perception of health. Also trending was health as a family responsibility yet female spouse were spoken of as being responsible for the health maintenance.

Memo: mental health was emphasized as a part of real health. A strong connection was made between PcA diagnosis and poor mental health. I began wondering if this was a development that was going to be seen in other groups.

Memo: Cultural objections of the DRE was raised. The claim was that this is not a practice welcomed in West Indian circles.

(MEMO: here the issue of sexuality features significantly and prominently as the issues of prostate cancer is discussed in focus group. Sexuality is associated e\with manhood and masculinity).

Memo: I noticed these men spent some time addressing the issues of general health and weight issues as they discussed prostate cancer. They made a connection between being overweight and increased prostate cancer risk.

**April 6<sup>th</sup> 2014** (West Indian American Couples)

These couples were very willing to share, disclose, and discuss. The concept of health as a family issue was expressed in various ways. Health maintenance was expressed as a shared responsibility. That is what I thought. The prostate cancer screening decision making as a shared responsibility was also the thinking that I had. Responsiveness of the men to their spouses as a part of their experience of prostate cancer screening decision making seemed to be more consistent as per their expressions than was their report of responsiveness to other health maintenance activities (e.g. dietary issues).

**April 14<sup>th</sup> 2014** (West Indian American Couples)

Session had to be encouraged to move because these participants were very engaged and talkative during the sessions. They seemed to be very passionate about the issues of health in general and seemed to be very passionate about the threat of prostate cancer and were very inquiring about why this is so. During this session the idea of divine punishment for some reason or another surfaced in the discussion. Participants seemed to be clued in to their experiences of stress, prostate cancer screening decision making experience, health maintenance, and self-assuredness. This was my impression after session was over.

Before entering the group session I was attentive to look for differences between this group and my African American Groups. I was struck with what I considered the similarities in the answers and experiences shared. The cultural apprehension about the digital rectal examination screening seemed to be a bit more emphasized in this group than in the AA groups that I had. Some group members seemed to emphasize the displeasure about this examination among the men that they knew. However, it was made very clear by men in the group that that was not their perspective on the matter. Several spouses of the men in the group emphasized the need for their partners to participate in the screening and expressed their encouragement and support for this participation in screening.

Memo: group appeared to be open to disclosing. Some group members appear to have known each other for a while but they continued to disclose freely and participate in session very openly.



Memo: During this group session some seemed to become very angry about stress related issues as the issues of stress was discussed.

Memo: Some group members seemed both concerned and angry at the fact that prostate cancer had such negative impact on men and families of African descent. Divine intervention/punishment surfaced in discussion as some group members reflected and commented.

Memo: Need for clarification sought to address difference between constructs that appear to be religiosity/spirituality ideas and apparent mindset of participants that is not simply religiosity/spirituality theme or simply not a religiosity/spirituality theme. Consultation and discussion completed with dissertation committee chair.

Memo: “Highs” and “Lows” were often described by participants in relational terms Here the relational experience in positive terms are important in that a positive relationship contributes meaningfully to screening and PcA diagnosis can compromise meaningful relationships

Memo: Knowledge, beliefs, and intentions affect meaning – it seems that way to me. It seems to be a theme emerging from certain codes in the data.

Memo: in attending to Relationships and the meaning it generated it seemed to me that there are times when relationships are expressed as concepts manifested in relationships between participants and other individuals/ or as relationships between participants and things. They still seem to be relationships. I guess these can be called “ambiguous relationships” as in “ambiguous loss”.

**APPENDIX F**  
**RESEARCH CODEBOOK**

<b>CODE ADDRESS</b>	<b>CODE MNEMONIC &amp; FULL NAME</b>	<b>CODE DEFINITION</b>	<b>WHEN TO USE THE CODE</b>	<b>WHEN NOT TO USE CODE</b>	<b>TEXT EXAMPLES OF CODING</b>	<b>THEMES</b>
6/41  6/28  1/28	<b>Hlt/Fam</b> Report of Individual and Family Health & Health maintenance in familial relational Terms	Participants understanding and defining health in individual and & Familial experiential terms – an experience that engages the family	When participant expressed understanding of health as meaningful in a relational family Setting	When health is expressed in ways that are not individualized or familial	“...in addition health is being able to live long and grow old together  “Health to very important to me. me is very important the concept of health means to me as a family. Health is wealth... ”  “...Health for me is more on the side if accepting the benefits of what you get by living Enjoying the benefits of life...”	<b>Uniquely Acquired Health Related Familial Conceptualizations</b>  Explanation of Theme: Health and Health Maintenance are conceptualized by participants as individuals in inter-connected in and/or familial terms.

3/34	Hlt/Fam				<p><i>“...Health is a mental wellbeing for my wife and I. physical health where we don’t have pain. And we eat well so, a well-balanced diet. ...”</i></p>	
3/406					<p>“...well I know my wife is the one who plays the lead role in our health maintenance. She manages the diet for example; she cut out fried chicken from our diet. Once she did that I started feeling good...”</p>	
1/204					<p>“Having that spiritual health. We focus on the spiritual side we</p>	

4/43

all believe in that. We all realize that we have to maintain that spiritual health, study the Word, having a relationship with God. The next thing is to transition to where my family is at”

“...Anyhow my mother would always pray, and part of her prayer was she would say this verse “As a hen sitteth over her chickens..” and she would say thank God I have ten children and they are all in good health.” Every single time she would say that as a part

					<p>of her prayer. And up until I got children I didn't realize the importance of what she was saying. Because if you have a child who is sick it affects you."</p>	
4/30					<p>"For me it means that it is very important that my children and my wife remain healthy. Very seldom do I find myself thinking about health as it relates to me. but I care a lot about the health of my family."</p>	
4/34					<p>"When I think about health I think about it in a very holistic way. I have learned over the</p>	



3/53

systems that are supposed to be replenishing you – it drains them so that you cannot get the nourishment you need for mental and physical health. It makes you need rest and it keeps you constantly like a low motor running. It drains you down...”

“...stress causes people to abuse food. Like things that are not necessarily good for the body it cause you to take in constantly those things that are not good for the body. They make people take in those things that are





4/91, 128, 131-136					<p>put enough thought into what stress does to all of us. Its damaging both physically and mentally...”</p> <p>“...well for me I actively participate. Set up all of my appointments I make sure that I follow on my physician’s regimen of recommendations, medications, and whatever it is. And secondly I take an active role in the management of my diet. I do not just cook but I shop so that I take an active role</p>	
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6/143	<b>Fam/Str/Rel</b> Stress is understood in relational terms	When stress is understood and spoken of by participants in terms of relationships with immediate family and extended beyond in all relationships	When participants report of the experience of stress as an issue affecting relationships with immediate family members and beyond to all general relationships	When participants do not refer to the effects of stress in relational terms	<p>“Abraham (pseudonym) just said stress is something that we would understand its everywhere. Whether its personal, its on the job, you may just have people you may come into contact with, you are wondering to yourself well what did I do them But its just there so as he was saying it’s not just so much the stress but how we relate to that...”</p>	
6/175					<p><i>“...Because for me and my beliefs, what’s beyond my</i></p>	

6/197				<p><i>control I believe that there is a greater force that takes care of that. That allows me to go through. You know if in your relationship, I can speak freely here in our relationships, my husband can tell when I am stressed because I can relate to him. I am freer, I am a lot more loving, I am not cranky, you know, I am just me. but when I am stressed, all these things I am just kind of paralyzed...”</i></p> <p>“...And I think that when you are stressed as a family you just</p>	
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					shut down you are not saying anything about what is wrong or that this is what is happening with me you just shut yourself down you are not communicating with the other partner then you the other partner is wondering what is it now? What did I do wrong? and I think... that with that stress now there is no communication and there is where you are going to find that with your relationship with your kids also because if you are going to found that with your kids when	
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1/107

they would say  
mommy or  
daddy you know,  
you are going to  
say I don't want  
to hear  
anything..."

"I think the  
things that would  
stress me out for  
instance I think  
would be  
probably be  
things around  
work and my  
family. Those  
are the two  
things that take  
up most of my  
time. I think  
work I am there  
most of the day  
if that's going  
good then things  
are good. If that  
not good then  
it's bad. The  
same thing with  
the family,  
relationships are

4/94

very important to me. if there are problems with family members immediate or extended I find those things can stop me.”

“...And she said well I just wanted you to know that I was feeling really stressed out because of your attitude (group laughter). so this stress the way we handle it, the way we deal with it, it doesn't only affect us personally that's the realization I came to but it affects everybody around us especially in the household.”

6/67	<b>Hlt/Rel</b> Health Understood in Relational Terms	Participants understanding of health is expressed in terms of relationships with immediate family and extended family	When Participants expressed their understanding of health in terms of relationships between themselves and immediate family members and with extended family and other relationships	When Participant expressed understanding of health with no reference to family and other relationships	<p>“... Once you are in a relationship, once you start a family. The health part most often become important when you start having kids. You start to see those kids depend upon you. and you want to be around to see them through. That is when health starts to show up as important...”</p> <p><i>“... And It is the foundation without health we basically can't do anything...”</i></p> <p>“...there was one saying they said that would really</p>	<b>Uniquely Acquired Health Related Familial Conceptualizations</b>
6/86						





1/20

4/34

it is all around...”

“: I guess for me, health is operating at a physical mental and emotional optimum or capacity. Would be health.”

“When I think about health I think about it in a very holistic way. I have learned over the years to apply that philosophy of health to myself. The philosophy of health for me is one which says that I am physically well and emotionally healthy. And so I am attentive to my physical

					health and my relationship.”	
6/49-51	<b>Hlt/SfCare</b> Health is expressed in terms of individual Self-care	Participant expressed an understanding of health in terms of individual self-care	When Participants’ response about an understanding of health is expressed in terms of individual self-care	When participants’ response about an understanding of health does not include terms of individual self-care	<p><i>“...for me most of my life it was an afterthought. I thought I was in good health until I was about 26-years old then I was floored with a chronic illness. ... after that wore off for a couple of years I just didn’t think about it until I was hospitalized about six or seven years ago and then I was brought back to the reality until I understand that I have to take care of myself....”</i></p> <p>“Then it came to me that I was destroying myself and I had to take</p>	
6/85						

					care of my life. And I really had a strong support system, I mean Sean and the boys they would be there saying mommy don't eat that. Whenever I would start to eat something they would warn me..."	
6/63	<b>Hlt/Pri</b> When Participants expressed an understanding of health as priority of life	Participant referred to health as a matter of significant importance and priority in life	When Participants' response to the meaning of health was expressed in terms of significant importance and priority in their lives	When participants' respond to understanding of the meaning of health and do not express their understanding of the meaning as of maximum importance in life.	"...it (health) is an afterthought for the most part until something touches you pretty close then you start to see. When my mom was diagnosed with the pancreatic cancer then I saw how fast she degenerated you know. It was so swift it came to me that health was the most	

4/455					<p>important thing in life . Yes you may have all these things in life but that's when health was obvious. That when it hit home what health really means to me. That's why to me its wellness its being whole, its well-being.”</p> <p>“Nobody has died of cancer diabetes and whatever it is. So coming to the United States has given me a different perspective about being cautious about health issues. So that why I follow my doctors, I go on my prostate</p>	
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4/619					<p>examinations, colonoscopy all kinds of stuff and so on. So in terms of any health issues I may need to loose 10 ponds...”</p> <p>“I think I am willing to start relinquishing some of that self-doctoring that I do. And I am very much interested in finding out about things that you are talking about here. I don’t even have a doctor, so that has been the impact that this has had on me. ...So that is the effect that this has had on me.</p>	
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					so I am going to go right out of this meeting and get a male family and follow up on this. ...”	
3/22	Fam/Self		When Participant Reported understanding or descriptions of Self	When there is no reported understanding of Her/himself	“...I think loving and appreciative and also frustrating...”  “...my wife and I, we are faithful towards one another, and we are diligent...”	
3/23						
<b>CODE ADDRESS</b>	<b>CODE MNEMONIC &amp; FULL NAME</b>	<b>TEXT EXAMPLES OF CODING</b>	<b>TEXT EXAMPLES OF CODING</b>	<b>TEXT EXAMPLES OF CODING</b>	<b>TEXT EXAMPLES OF CODING</b>	<b>THEMES</b>
6/720  1/198  2/29, 26,	<b>PcA/Meaning</b> The meaning attributed to PcA and Pc A screening based on participants’ “knowledge” about PcA	The cognitive, affective and relational understanding that participants experience due to their knowledge about PcA and PcA screening	When participant talked about his/her beliefs, knowledge, and intended actions about PcA and her/his Family	When there is no expressed beliefs, knowledge, or intended actions about PcA and his/her family	“...The only reason we have more prostate cancer is because we do not eat enough pasta ... and he goes, Italians do not have a high rate of that disease because they eat a lot of pasta...”	<b>Familial Meaning Generated by Notions of Knowledge, Beliefs, and Intentions</b>  Explanation of Theme: Participants’ report of their individual and familial experiences of the

<p>3/6, 31,127</p> <p>3/529</p> <p>4/698</p> <p>3/112</p>					<p>“...I would say ...and I don’t know about prostate cancer if there is something that’s hereditary but I would say that in terms of our family knowledge is super-important. And so you know if there are things that you can’t avoid because they are in your family history in terms of your genes then you really have to be prudent to be healthy in other ways so that what you can’t escape you can be in better shape so that you can deal with it</p>	<p>meaning of the PcA Screening decisions generated by individual and families’ notions of their knowledge, beliefs and intentions</p>
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6/526					<p>in other ways. So I would say in terms of our family history our discussions would be what is the family history...”</p> <p>“...well prostate cancer is not an issue in our family. But such things as asthma and heart disease are issues in our family. So the issue of reaching 40-years old is a morbid issue. As my wife said I have 2 uncles that died in their forties. One was forty seven so I haven't reached his age as yet. 2 were 44 so... When I reach 40 my doctor told</p>	
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6/566

me I have to do the prostate examination, but I didn't like the prostate examination. I didn't like it the first time, I didn't like It the second time either. But I keep doing it..."

"... We have to keep in mind the history. Some of the history. On the education about how the screening is done our diet had a lot to do with it. Prostate cancer and cancers in general was not something black people got many years ago. ... When we got a little bit more money we

<p>6/656</p> <p>3/532</p>				<p>started to eat like Europeans. All the gravies and all the this and all the that and so its like years ago they did a study about eating pork. Black people eating pork had high blood pressure. They looked at the whites the Spanish, the blacks, and the Polish. The polish ate more pork that everybody but the effects on the body was different because of the lifestyle. If we go back we will remember the fruit for the healing of the nation...”</p>	
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					<p>“I was talking with someone who said that diet and some of these things are good to be attentive to. He also discussed sexuality and talked about the different approaches to sex and the timing and those things. And he noted in his research that something about the frequency of sex associated with better prostate health.”</p>	
6/539	<p><b><i>App/Know</i></b> Participants Appeal for more knowledge</p> <p><b><i>InAc/Knowledge</i></b> Inaccurate notions that participants hold</p>	Participants expression of their need for additional knowledge based on their perspective of their depth of	When participants expressed statements about their need for increased knowledge levels on PcA matters	When participants expressed no statements about their need for knowledge	<p>“.... I don’t know all that goes into it. And I think I really have to , to , this awareness, I have to begin to pay a lot more</p>	

		knowledge about PcA and PcA screening benefits		about issues related to PcA,	<p>attention. I have to pay a lot more attention to it. Whether its genetics, whether its environmental, whether it's the result of lifestyle. I really don't know all that goes into it. But I would really, really like to know what are the factors that contribute to it. Because then we can begin to make the kinds of changes that. Or address the disease in some shape or form..."</p> <p>"...I would say ...and I don't know about prostate cancer if there is something that's hereditary but I would say that in terms of our family</p>	
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					<p>knowledge is super-important. And so you know if there are things that you can't avoid because they are in your family history in terms of your genes then you really have to be prudent to be healthy in other ways so that what you can't escape you can be in better shape so that you can deal with it in other ways. So I would say in terms of our family history our discussions would be what is the family history..."</p>	
	Notion of participant's				"...The only reason we have	

	knowledge				more prostate cancer is because we do not eat enough pasta ... and he goes, Italians do not have a high rate of that disease because they eat a lot of pasta...”	
<b>CODE ADDRESS</b>	<b>CODE MNEMONIC &amp; FULL NAME</b>	<b>TEXT EXAMPLES OF CODING</b>	<b>TEXT EXAMPLES OF CODING</b>	<b>TEXT EXAMPLES OF CODING</b>	<b>TEXT EXAMPLES OF CODING</b>	<b>THEMES</b>
6/734	<i>Sup/Int/Mdset</i> Mindset about Sense of Supernatural Intervention in Cause/Cure of PcA	Participants interpreting PcA as life event as having a meaning based on a settled Mindset	When participant Reported personal or Familial attitudes about PcA Impacts on WIA/AA Community as based on a particular mindset	When there is no reported personal/familial attitude towards PcA and the WIA/AA Community based on a particular mindset	<i>Sup/Int/Mdset</i> “...He had a mindset that said if that is how God meant it to happen that’s how it was going to happen.”	<b>Settled Mindset Conditioning Meaning</b>  Meaning of the Theme: The manner in which participants and families’ have settled patterns of thinking (mindset) that they have inculcated over time that condition the meaning of their experiences about PcA and PcA screening

						decision making
	<p><i>Source/ill</i> Mindset about source of illness</p>	<p>A pattern of thinking about the source or causes of PcA among the men of African heritage</p>	<p>Participants reported a particular belief and thinking about the root causes or source of PcA among men of African heritage</p>	<p>Participants reported no particular belief about the source of PcA Among African Heritage men</p>	<p><i>Source/ill</i> “...why is it that prostate cancer is such a black men problem globally it seems to be the case. It is a spiritual problem. There is a shortage of black men as is. Some of them in prison and so on. I like to look at things in a spiritual way sometimes because they say we wrestle not</p>	

					against flesh and blood but against spiritual wickedness in high places.	
6/776	<b>Trv/Mdst</b> Mindset to trivialize PcA diagnosis and appropriate screening behaviors	This is manner of thinking that trivializes both PcA screening behaviors and PcA diagnosis	Participants reported sentiments and thinking that suggested PcA Screening behaviors and PcA diagnosis are taken lightly and trivially	When there is no indication of trivializing of the need for PcA screening and of the diagnosis of PcA.	<b>Trv/mdst</b> “...no it happens bit for some men the defense mechanism is to not let it get beyond the jokes of not screening...” “...but for the general community of black men I think there is not serious conversation about the disease...”	
6/746	<b>Sec/Mdst</b> A Mindset of dealing secretly with the disease	This is a mindset that says I will deal in secrecy with PcA. The diagnosed individual intends to deal with the	Participants reported of desires and behaviors of dealing with diagnosis in secrecy	Participants did not appear to be willing to deal with the diagnosis in secrecy	<b>Sec/Mdst</b> When we spoke to his wife she said he was bearing the burden since about 2008...	



		diagnosis in secrecy			<p>when he was diagnosed and then when he was diagnosed he actually kept it a secret from his wife and kept it a secret from people. “</p> <p>“...Often you hear about people going through a crisis you will hear them say, “Don’t tell my wife or don’t tell my husband...”</p>	
6/848	<b>Res/Mdst</b> A Mindset of resignation after diagnosis	This is a mindset that sees diagnosis as something from which a person cannot recover – certain death hence a resignation to designated outcomes	Participants reported interpretation and meaning of the disease as a thing that has a definite and specific fatal outcome.	When participants do not report certain death resulting from PcA diagnosis but rather possibilities for recovery after appropriate interventions.	<b>Res/Mdst &amp; Bel/Mdst</b> “...one of the prevailing beliefs when you hear of the diagnosis of prostate cancer is that it is a death sentence. You start calculating. Oh, poor guy he doesn’t have	

6/831					<p>long more..."</p> <p>"It is either denial or it is as if when you find out that you have this disease its as if nobody lives with it. You understand? When someone finds out they have this disease they die. So when someone finds they have this disease if they think about it maybe they will die faster. So they may say let me just put it and the back of their mind and say let me live my life."</p>	
6/839	<b>Bel/Mdset</b> Mindset about beliefs surrounding PcA	A Mindset or way of thinking that suggests settled beliefs about the disease and such	When participants reported beliefs that people have about PcA and PcA screening that are	When there are on settled beliefs reported and instead there is a	<b>Fte/Mdst</b> <b>Bel/Mdst</b> "They live with the belief that there is	

6/637		beliefs seem difficult for participant to change.	settled and difficult to change.	searching for information about the disease	<p>something that they did that caused this illness to happen to them. And sometimes they interpret it as a plague as something that I did over the course of time.”</p> <p><b><i>Bel/Mdst</i></b>  “...I was talking with one of my church brothers yesterday. In fact I invited a particular brother to come and I didn't see him. So I asked another person about him. And this person reported to me that he said he is not coming because they only talking foolishness</p>	
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6/795					<p>there. The only reason we have more prostate cancer is because we do not eat enough pasta...”</p> <p>“...when I used to take my father to the doctor and he was over fifty and that PSA level increases. And when they said that he had ti take that rectal examination he never took it. He said, “well something have to take us”. He said it increases and that just part of life.</p>	
6/841	<p><b>HlpS/Mdst</b> Help seeking Mindset - A mindset people maintain about help</p>	<p>This refers to the mindset that a person develops that relates to his willingness or</p>	<p>Participants reported a way of thinking that relates to willingness or unwillingness to</p>	<p>When no indication is indicated about help seeking behaviors in</p>	<p>“After diagnosis I think that patient needs to be educated. I</p>	

	seeking behaviors in times of Screening and/or PcA Diagnosis	unwillingness to seek appropriate help in PcA screening or intervention before and after PcA diagnosis	seek screening or help after diagnosis	PcA screening or in post-diagnosis for PcA	think we need more community involvement and tell the young men that they need to get tested because now they have so many kinds of new treatment. Because if they are being treated early because if they are treated early because a lot of people if they are treated early the prostate cancer do not really kill them now.”	
6/859	<b>Inv/Mdst</b> A Mindset of invincibility in dealing with PcA.	A Mindset that thinks of one-self as intrinsically capable of dealing with PcA diagnosis without appropriate intervention	When participants reported about a general attitude of dealing with PcA screening and/diagnosis in invincibility terms that suggests person is intrinsically capable of dealing	When participant does not report of intrinsic capacity for dealing with PcA & PcA screening in invincibility terms.	<b>Inv/Mdst</b> “...And for me they had an air of invincibility. And they would say ‘what’s that?’ And they just kept on living and they refused	

			with the diagnosis and consequently no need for PcA screening.		treatment...my assessment especially for my older uncle. It was a feeling of invincibility.”	
5/791 6/856	<b>Fr/Mdst</b> A Mindset of fear when addressing possibility of PcA Diagnosis	This is a mindset that makes fear a dominating emotion after diagnosis or when facing the possibility of diagnosis	Participants reported a type of paralyzing fear that dominated a diagnosed person that hinders capacity to take initiatives to help in dealing with the diagnosis.	Participants reported no paralyzing fear in dealing with PcA screening or diagnosis.	<b>Fr/Mddst</b> “There is a fear attached to it too. Fear.”  5/791“...if someone is diagnosed. I think it would affect the family in different ways. Because first when you hear the word cancer like you get scared and people get angry, they get angry at themselves especially if you have been taking care of themselves.”	

4/369				<p>“And some people kind of deal with it in another way. Some people are embarrassed to say they have prostate cancer because some people like me thought that when people have prostate cancer their sexuality is gone. So that is not something that you want to be out there. So you have it you try to keep it quiet as a secret. But one I realize and I was educated as to what it is and that even though you have the surgery that does not mean that that is the end of your sexuality.”</p>	
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6/	<p><b>Fte/Mdst</b> Fate as an inevitability of PcA Diagnosis - A mindset that regards PcA illness as simply FATE that one has to live with.</p>	<p>This is a mindset that thinks of PcA diagnosis as a matter of fate that one has to live with and deal with its consequences.</p>	<p>When participants reported of approach to dealing with PcA as a matter of fate and the inevitability of dealing with the diagnosis and whatever consequences it brings.</p>	<p>When participants reported responses of dealing with PcA screening and PcA diagnosis in terms that suggests that one has capacity to take initiatives to help oneself.</p>	<p><b>Fte/Mdst</b> “...well in the example that .... cited we noticed that early; to him this was fate and he accepted it and just go along with it....”</p> <p><b>Fte/Mdst</b> <b>Bel/Mdst</b> “They live with the belief that there is something that they did that caused this illness to happen to them. And sometimes they interpret it as a plague as something that I did over the course of time.”</p>	
1/83	<p><b>Rel/HP/Mdst</b> Mindset about relationship with a Higher Power</p>	<p>Pattern of thinking that a participant reported that suggested dealing with PcA through</p>			<p><b>Rel/HP/Mdst</b> And sometimes we even shut God out and we put up these</p>	



		one's relationship with a higher power.			barriers and we are inside like a cell. And that is how I look at stress. The bad things are like the stress and its what we do.  "Sometimes for me, God is my stress reliever. If I pray about the situation and sometimes he works it out and sometimes I really not trying to work things out on my own."	
4/719	<b>PosTmt/Mdst</b> A Mindset that sees treatment of PcA in a positive peace generating experience	An expressed understanding of PcA Screening in a reframed manner that suggest a positive peace generating experience based on the discovery/revelation from the	Participant reported a thinking about PcA Screening in terms that suggest a reframed approach that sees PcA screening as an important positive experience	Participant did not reported a thinking about PcA Screening in terms that suggest an important positive experience	<b>PosTmt/Mdst</b> "Emotional and psychological trauma. The third time around. This is what he told me live in this moment. So I have found that in dealing with	

		Screening			prostate cancer the key is to have the frame of mind in which you enjoy life and live in the moment because as I said I have been through depression, I have been through; when people talk about a roller coaster experience do not underestimate it. That roller coaster experience can be difficult.”	
<b>CODE ADDRESS</b>	<b>CODE MNEMONIC &amp; FULL NAME</b>	<b>CODE DEFINITION</b>	<b>WHEN TO USE THE CODE</b>	<b>WHEN NOT TO USE CODE</b>	<b>TEXT EXAMPLES OF CODING</b>	<b>THEMES</b>

<p>6/672</p> <p>2/176</p>	<p><b>Shrd/Htl/Resp</b> Mutual commitment of partners to share in each other's health management</p>	<p>Shared responsibility for health management within the family refers to an expressed commitment of partners to share in their mutual health management</p> <p>Nature of Support in the Family</p>	<p>When participants refer to mutual commitment to supporting health management in each other</p> <p>When Participant responded to PcA through actions or inactions based on familial or non-familial relationships/settings</p>	<p>When there is no expression of mutual commitment to support health management among partners.</p> <p>When Responses to PcA through Inaction/actions are based on things other than familial or non-familial relationships</p>	<p>"wife would be understanding and work with the male partner through the difficulties."</p>	<p><b>Meaning and Motivations Generated in Relationships Contexts</b></p> <p>Explanation of Theme: The Nature of the Relationships within families and between Families and Health Promoting Parties and Entities.</p>
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	<p><b>Fam/Com</b> Nature of Family Communications</p>	<p>This refers to the reported commitment to or practice of engaging in familial communication particularly on health related/PcA matters</p>	<p>When participants reported practices of familial communication particularly on PcA matters.</p>		<p>If you weren't ...having good communication a diagnosis may not...draw you closer. Because if you are not communicating especially on issues of health then a diagnosis will set in fear and stress and then you know then all the other things start working in your mind and then you do cling to one another for support or you just shut down and clam up.</p>	
	<p><b>Mut/Dis</b> Mutual Disclosure of Illness within Family</p>	<p>The Nature of Disclosure about PcA Screening and PcA health and diagnosis within the partners in the relationship</p>	<p>Participants report about the quality of the disclosure about prostate screening, prostate health and prostate diagnosis to the partner within the familial</p>	<p>Partners did not report on disclosure quality between partners within the relationship</p>		

			relationship			
6/672	<b>Mut/Eng/Mut/ Sup</b> Mutual Engagement of partners in Family Health Maintenance and mutual support/encourageme nt from partners for PcA screening	Family's health management is managed and experienced as a collaborative responsibility between partners	When participant reported family's health as managed by partners as a family collaborative responsibility of the partners in the relationship	When the family's health management is not reported as a collaborated experience between the partners	<p>“...They (Blackmen) would get a lot of things as the women in their lives push them but for a lot of the men they don't like going to the doctor. Whereas our European men oh Bobby did we got to go to the doctor. And so Bobby goes to the doctor o.k...”</p> <p>“One of the things I would like to add is that it is very important for those who have mates or partners that they are included in this</p>	
2/488						

2/691

thing. As a matter of fact at my house everything is fair game. As an example my friend David there our wives are all over us. Violet is on him. Diana is on me and it drives me up a wall. But I know it is all out of love..."

"When my prostate thing came up a few wives asked me to talk to their husbands to make sure they go and get checked and stuff. So I talked to them they listened but when I asked them if they went to do the

					screening; if they attempted to go or did you go. It was no, no, no none of that.”	
3/159	<b>HCP/Rel</b> Relationship Between Family Members and Health Care Providers	An expression of enhanced or compromised health management based on relationship with HCP and/or health entity	Participants reported understanding of enhanced or compromised PcA health management based on quality of relationship with Health Care providers and entities	Participants did not report enhanced or compromised Health management due to quality of participants and HCP/health can\re entities	<p>“... It took me a long time to start going to the doctor. I am one of those people that had that macho thing going on and I didn't go. But at 60-years-old my wife suddenly convinced me to go and that's when I had my first check...”</p> <p>“...the trust in the medical profession has been diminished because many times they see us not as patients but as a meal ticket...”</p>	

2/245					<p>“...My thought on health is as I listened to everybody else is that the thing that is keeping me is that I know my own body. I have to really know my own body. I know how I feel on a daily basis. If something is wrong I do not hesitate to see the doctor....”</p>	
3/174					<p>“...you know, he (doctor) was stacking me up on medication. Nothing that I said he really wanted to hear. He just said well, you are not doing so and so. And so well I really did not want to go to</p>	



2/255

him. A lot of times I really did not want to keep the appointment. I didn't want to go to him because he would say you too fat, you're too this, you're too that. And I would reschedule the appointment. And I think God worked it out where I had surgery at another hospital and when I went there my Blood pressure was high and at that time it was a normal thing for me. Well it was a lot for me."

"Yes and/ but I tell the doctor what's wrong with me. I

					tell him this is what is happening. I want you to check this. So that is the kind of relationship I have with the doctor; with both of the doctors that I have.”	
1/117	<b>His/los/Relt</b> Participants experienced “highs” & “Lows” in familial Relational Terms	Participants reported their experiences of “highs” and “lows” in their lives as rooted and sourced in familial relational terms	When participants’ reported the meaning of “highs” and “Lows” of life experiences in familial relational sources and terms.	When participants reported the meaning of “highs” and “Lows” in their lives and such reports were not rooted as sourced in familial relational terms	<b>His/los/Relt</b> “My highs is really when my family is at the best in coordinating, especially when we are on a spiritually high level. When we are there together it brings me most of the highs in my life. And most of the lows is opposite. When we not going in accord.”  <b>His/los/Relt</b>	

1/135					<p>“Not being able to provide for yourself and that is one of the lows and for me the highs is when I have my family members, the people, I have their support from them. I have the confidence in them. I have that relationship with them. “</p>	
6/316					<p><b>His/los/Relt</b>  “My highs is when I met my wife when we fell in love  Those were my highs. ...when io got married,  when I first had my daughter, and felt that .. the first child when you felt that feeling it’s a feeling like no</p>	
2/370						

2/328					<p>other.”</p> <p><b>His/los/Relt</b> “Yes my highs was taking the foundation that my parents gave me and becoming a professional man and going back to school and becoming a good Christian man and being a good father. Getting married. And my lows getting divorced, becoming depressed, and getting a DUI. Those were the low parts you know.”</p> <p><b>His/los/Relt</b> “My low is about ten years ago I was divorced after 10 years . I</p>	
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1/164				<p>hit rock bottom. Then joy came about 7 years later when I got remarried to my second marriage going on eight years now. That's my high. In addition to that it is my children."</p> <p>"I share some of what he said in terms of not being in control. To feel that you have lost control of your position in the family as the male figure. If you are not there and you that gives you a low. If you have lost control or your position as a figure as a male role model, that can</p>	
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4/380		PcA diagnosis	sexual capacity pertaining to relationship with partner	compromised with partner	<p>say they have prostate cancer because some people like me thought that when people have prostate cancer their sexuality is gone. So that is not something that you want to be out there. So you have it you try to keep it quiet as a secret. But one I realize and I was educated as to what it is and that even though you have the surgery that does not mean that that is the end of your sexuality.”</p> <p>“Guys, gentlemen I can’t explain once you are dealing with prostate cancer</p>	
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					<p>issues for the first time in your life sex becomes an important issue and that is a whole different dimension all by itself.”</p>	
4/885					<p>“...I don't think I really delved into the area of the effects of prostate cancer on masculinity, virility, and whatever else. Stuff. It is good to know that , I don't know if I am saying this right but for me it would be very scary because I like sex.”</p>	
3/384					<p>“Some people do not want to know. Because of the fear of</p>	



1/329				<p>something. It might be the fear of sexuality and poor sexual performance. That is something that is out there pretty much. And so some people do not want to know and to deal with that reality.”</p> <p>“...Yes that is the thing. The other part of it is longevity. The risk is so dim so that if you weigh sexuality versus longevity, I would choose longevity. But if I can have both I would take both (Group laughter) . because you don't want to put sexuality at the</p>	
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5/826					in mental health. Men don't talk about their issues."	
5/721					"But I think it all depends on the family. I know some families whether they are not educated about it or not but these matters are not the foremost things on their minds so the conversations do not happen unless somebody goes in there and say look you guys need to worry about this and this and that. And I know you need to look at this. So I know it's a lot of families unless	

2/895				<p>the family has that orientation it is just not going to happen. “</p> <p>“In my present household. This is not something that we talk about regularly. But when it comes up once it comes up, oh my goodness everybody is walking over each other about it. In my situation Anise (daughter) wen in and check on my situation, my wife went in and checked, and whatever they found out they would come and tell me...”</p>	
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CODE ADDRESS	CODE MNEMONIC & FULL NAME	CODE DEFINITION	WHEN TO USE THE CODE	WHEN NOT TO USE CODE	TEXT EXAMPLES OF CODING	THEMES
6/505	<b>Cul/DRE/Dslke</b> Dislike for DRE due to culturally rooted beliefs	A stated dislike for DRE due to historical culturally based beliefs and experiences	When Participants reported about dislike and unwillingness to participate in DREs based on historic cultural attributions, beliefs, and understanding	When participant reported of dislike for DRE that expressed no root or basis in cultural attributions, beliefs, and/or understanding	<b>Cul/DRE/Dslke</b> “Yes I did. It was the doctor who did not do it. And I notice that most men do not like to have this test done on them. As a nurse I notice that when I talk to men about this they say “I don’t want t no doctor to put their hand up in my butt”. Excuse me “I don’t want that”. So that is what I notice.”	<b>Culturally Based Rooted Patterns of Meaning</b>  Explanation of theme: The nature of culturally transmitted beliefs, habits, customs and patterns that impact the meaning of PcA Screening experiences and decisions.
6/519	<b>Cul/Bel/PcA</b> Culturally rooted beliefs and thoughts about PcA Screening	A Stated understanding of participants and their community’s responses to PcA	When Participant Communicated about responses or Causes of PcA & PcA Screening in	When participant communicated about responses or causes of	“...when you talk about this DRE thing here, listen Sir, joke or no joke, we do	

<p>3/156</p>		<p>Screening that suggested culturally rooted bases.</p>	<p>manner that suggested a specific Cultural basis or motivation</p>	<p>PcA screening in a manner that did not suggest any specific cultural basis or motivation</p>	<p>not like the fact that nobody whether it's a man or a woman pushing something up their butt..."</p> <p>"...well I know ... I was a corp. man in the Navy and I pay a lot of attention to history. You know there was a study done in Tuskegee in which they inject black men with syphilis and the black men would go to the doctor and say this is what is going on and the doctor would say oh you're O.K. And even though it was 40 black men that permeated</p>	
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6/687

throughout the whole culture in the south and so the trust in the medical profession has been diminished because many times they see us not as patients but as a meal ticket...”

“...Now when it comes to our black men because of the history of slavery and everything else the degrading that black men went through the black men have that homophobic attitude. I am not gay. Therefore for a lot of black men they would not get pass that. So they won't go

					and get the test. .. the cultural, the history, the diet...all the variables make the whole situation.	
4/675 Cult/DRE Fears  4/744ffCult/DR E Fears	<b>Cul/DRE Fear</b> Culturally Based Fear of DRE	Fear of DREs based on culturally rooted beliefs and ideas	When participants reported ideas of people's refusal to participate in PcA screening behaviors based on culturally rooted ideas such as homophobia etc.	When participants reported fears of PcA based on culturally rooted ideas.		
					"...One of the key things when dealing with prostate health and prostate cancer whether it is prostatitis or whatever, my brother was diagnosed with prostatitis and he died about a year ago...he had some of the same	



4/675

symptoms that I had but he was never diagnosed – he had all the symptoms that I had. But one of the key things is the quality of life. I signed up for surgery because my focus was not so much the quality of life but the quantity of life...”

“...I think when you talk about the culture piece and for us West Indian/Caribbean men. The idea of anybody touching that part of their body; that’s like blasphemy. And having been through the process myself I

					<p>mean as one who was actually a proton treatment patient and one who has been on doctor's care for a while, I guess I can speak about the number of digits that I had to endure..."</p>	
<p>4/746</p>					<p>"Caribbean men do not want to have anything to do with that region of the body. "</p>	
<p>4/540</p>					<p>"I am not one of those guys afraid of the doctor. I go to the doctor regularly. I f I have a headache I go to the doctor. I do my annual tests and everything. My wife is a nurse</p>	

4/509					and I have to beg her to go to the doctor but I am not afraid to go to the doctor. I was very disappointed that time when I went to the doctor when I asked him for the PSA test he said we don't do that any more."	
5/784	<b><i>Cul/Talk</i></b> Culturally based Unwillingness to talk about PcA & PcA Screening	Unwillingness to talk about PcA and PcA screening based od culturally based patterns of	Participants reported an unwillingness to communicate on PcA Screening in	Participant did not report unwillingness to communicate about PcA	"I was going to say, I mean growing up on the island people	

3/342		behaviors	terms that were rooted in cultural bias against talking about PcA diagnosis	diagnosis in culturally based terms.	did not talk about prostate cancer.”	
3/355					<p>“...It is a denial thing. You don't want to .. Men do not really want to talk about this. They talk about.”</p> <p>“The tough situations that we as Black men have to deal with from time to time. We like to get together and talk about softer issues. And the extreme issues do not or rarely come up. Because like anybody else we like some good times along with the bad and like many things with black men it is a</p>	

					tough situation to make life work from day to day. So the real issues do not come up too often...”	
3/378	<b>Cul/Neg</b> Attitude of negligence in PcA health matters	Participants report of an unwillingness to participate in PcA Screening due to a cultural pattern of negligence about health matters	Participants reported unwillingness to participate in PcA screening due to a cultural pattern of health neglect	Participants did not report PcA screening neglect due to a cultural pattern	“...There are two people I know who died with it, Chuck, and when I asked him while he was in the hospital. I asked him, why did it get so bad? He answered and said I tell you the truth I did not take care of myself. I should have gone and taken care of myself. And it ended up taking him...”	
3/621	<b>Cul/Mas</b> Culturally related meaning of Masculinity	When participant reported views of masculinity that are culturally	Participants reported understanding of masculinity in	Participants did not report on masculinity in terms that are	“A lot of tis hinge on the male. For them they seem to	

		generated	terms that seemed to be culturally based	culturally based	<p>think that their manhood is linked on that their sexuality. For a lot of men a lot about their manhood is linked on their sexuality. Their ability to perform. Sexual performance and, therefore, losing that is losing your soul. And if that's understood quite well And a lot of that if it is communicated quite well with your spouse you might take a different approach to this matter.”</p> <p>“Some people do not want to know. Because of the fear of</p>	
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3/641				<p>something. It might be the fear of sexuality and poor sexual performance. That is something that is out there pretty much. And so some people do not want to know and to deal with that reality.”</p> <p>“Well I think if it is actually deep rooted just from the origin of man but probably more so now when we have some external factors that or what people identify as masculine. Oh this is a man that’s not a man and it may play out more as the spouse and</p>	
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					women in general if we try to emphasize the fact that there are all the other things that make you a man or there are other things that you need to be concentrating on if you are taking care of your health it's really, if you have a family, that's the manly thing to do. The same way we equate work with being a man then if we can build up those things and take the emphasis off the sexuality part..."	
6/	<b>Cul/Fd</b> Participants attached meaning to food based on cultural orientation	Participants express understanding of food as part of a cultural experience	When participants refer to food and its role in participants' lives as a culturally based experience	When participants refer to food with no indication of	"...So we look to food most of the times and most of us coming from a Caribbean	



				<p>the culturally based meaning of food in participants' lives</p>	<p>background we know that food is comfort. You know you go to a social event mommy and daddy cook you don't eat they look at you and they say why don't you eat or why are you not eating? You tend to look thin they say you need to get some meat on you. So coming from a cultural background also that is something that we also have to take into account. Fd Culture Cultural relationship to food) Coming back to stress and health when we are stressed we tend to not take care of ourselves as well as if we</p>	
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					weren't stressed."	
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## Appendix G Generated Model

