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**A QUALITATIVE EXAMINATION OF PROSTATE CANCER TREATMENT
DECISION-MAKING AMONG BLACK MEN**

BY

LINDA OTTLEY

B.S., Nursing, Catholic University of America, 1984
M.S., Nursing Advanced Practice, Texas A&M Corpus Christi, 1991

DISSERTATION

Submitted in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Philosophy

Nursing

The University of New Mexico
Albuquerque, New Mexico

December, 2019

DEDICATION

I dedicate this dissertation to my son, Ty Danet, who has traveled with me on this journey for almost half of his life, and who I am proud to say has followed in my footsteps by presenting at mathematical conferences and successfully publishing his work. To my parents, Alma Ottley and the late Honorable Senator Earle B. Ottley, you lovingly instilled values of hard work, life-long learning, determination, and service to others. Because of them, I have led a very privileged life and now try to repay for some of my blessings by giving a voice to the voiceless. To my brother Larry, and my sisters, Diane, Judith, and Patrice who provided emotional support along the way, thank you.

I also dedicate this work to the brave men and women who were tortured and/or killed so that I could be free from slavery. I write in memoriam to Trayvon Martin, Michael Brown, Eric Garner, Tamir Rice, Walter Scott, and Philando Castile, among others, who were the victims of a system where Black lives don't matter, and the countless number of people of all ages, races and genders whose lives were senselessly cut short by escalating violence.

Finally, I dedicate this to the men who shared their stories. Without them, I would not have been able to conduct this research, learn of their struggles, or offer their stories as rays of hope.

ACKNOWLEDGEMENTS

Thanks to Dr. Jennifer Averill, who suffered an unimaginable loss, but was determined to see me through to the end, and to my other committee members, Dr. Jamal Martín, Dr. Mark Parshall, Dr. Geoff Schuster, and Dr. Dorinda Welle, who continued to provide their knowledge, encouragement and advice. I would also like to thank Dr. Tracy Downs who has always provided help and inspiration when I needed it.

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ABSTRACT

This ethnographic study explored the experience of treatment decision-making among urban Black men who were diagnosed with prostate cancer in San Diego, California. Specifically, this research was conducted to further understand the decision-making process among Black men and the barriers they face when making treatment decisions about prostate cancer. The study is important because prostate cancer disproportionately affects Black men in the United States, and yet they are underrepresented in research studies (Randolph, Coakley, & Shears, 2018). These inequities are poorly understood and need considerable analysis and exploration. Still unclear is the possible effect of historical trauma or negative healthcare experiences on these treatment decisions. Findings revealed that Black men diagnosed with prostate cancer need a trusting patient-provider relationship, accurate and complete treatment information, and enough time to make effective treatment decisions.

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Chapter 1

Introduction

The Invisible Man-He is missing from the health care system. He is less likely to hold a job that provides health insurance. Otherwise, he is underinsured. Despite chronic poverty that cries out for relief, he often slips through the cracks of a frayed social safety net. Medicaid, focused on pregnant women and children, rarely includes him. He bears a disparate burden of disease. He dies early and struggles frequently against structures that render him invisible” (Dr. Keith Elder)

My experience as a nurse practitioner who treats men with prostate cancer led me to see the need for this research. I found that many Black men who were diagnosed with prostate cancer often did not understand the multiple treatment options, or they were dissatisfied with their chosen treatment. Many suffered in silence for years, but some of them opened up to me.

It is possible that they trusted me; studies have shown that Black patients identify trust as being very important to their relationships with their healthcare providers, and they are more satisfied with care when their providers are racially concordant (Saha, Komaromy, Koepsell, & Bindman, 1999). This trust could also be related to my position as a nurse, since nurses consistently rank as the profession with the highest levels of honesty and ethics (Riffkin, 2014).

The Health of Black Americans

Black Americans continue to experience inequities in health despite major advances in healthcare (American Cancer Society, 2019a; Betancourt & Maina, 2004; Institute of Medicine, 2003; Kennedy, Mathis, & Woods, 2007). Even when they have equal access through integrated healthcare systems, such as the Veterans Health Administration (VA), Black people continue to experience considerably poorer health outcomes and less satisfaction with care than Whites (Hausmann, Gao, Mor, Schaefer, &

Fine, 2013, 2014; Saha et al., 2008). Black patients also report being spoken to and treated disrespectfully by healthcare providers, and they experience less satisfaction than White patients (Cheatham, Barksdale, & Ridgers, 2008; Cooper-Patrick et al., 1999; Doescher, Saver, Franks, & Fiscella, 2000; Paez, Allen, Beach, Carson, & Cooper, 2009; Griffin, Allen, & Gunter, 2011; Taira et al., 2001). These inequities result in Black Americans having higher morbidity and mortality rates from most cancers and preventable illnesses than White Americans (Institute of Medicine, 2003; Surveillance, Epidemiology, and End Results Program [SEER], n.d.). Unfortunately, many Black people perceived their cancer risk to be low (Friedman, Corwin, Dominick, & Rose, 2009; Orom, Kiviniemi, Underwood, Ross, & Shavers, 2010; Xu, Janisse, Ruterbusch, Ager, & Schwartz, 2016).

Prostate Cancer Inequities

The overall incidence of prostate cancer has been decreasing in the United States. Black men continue to have higher morbidity and mortality rates than men of all other races and ethnicities (American Cancer Society, 2019a; Odedina et al., 2009; Siegel, Miller, & Jemal, 2015). The exact reasons for the inequities are not clear (Albano et al., 2007, Armstrong, Hughes-Halbert, & Asch, 2006; Barocas & Penson, 2010; Bell & Duffy, 2009; Benkert, Peters, Clark, & Keves-Foster, 2006; Betancourt & Maina, 2004, Carpenter et al., 2009, Cheatham et al., 2008; Chornouker, Dalton, Borysova, & Kumar, 2011; Do et al., 2010; Fitzmaurice et al., 2013; Halbert et al., 2009; Halbert, Armstrong, Gandy, & Shaker, 2006, Jones, et al., 2006; Jones, Underwood, & Rivers, 2007; Odedina et al., 2004; Schwartz et al., 2009; Shi, 2010; Steenland et al., 2011; Underwood et al., 2004). Decisional regret often occurs after prostate cancer treatment, and Black men have

been found to have a higher risk of experiencing decisional regret after treatment (Holmboe & Concato 2000; Morris et al., 2015). Lack of shared treatment decision-making has been found to increase decisional regret in men diagnosed with prostate cancer, and limited knowledge about prostate cancer has been found to increase decisional conflict (Kaplan et al., 2014). The numerous treatments for prostate cancer also have long-term adverse effects on health-related quality of life (QOL; Steenland et al., 2011). Decisional regret often occurs due to treatment side effects such as erectile dysfunction and urinary incontinence, which can adversely affect QOL for Black men to a greater extent than for individuals from other racial/ethnic groups when diagnosed with prostate cancer (Chornoku, Dalton, Borysova, & Kumar, 2011; Collingwood et al., 2014; Diefenbach & Mohamed, 2007; Goh, Kowalkowski, Kazer, Knight, & Latini, 2012; Katz, 2007; Morris et al., 2015; Orom, Biddle, Underwood, Homish, & Olsson, 2017; Parker, Montgomery, & Wood, 2009).

Black men with prostate cancer who undergo treatment for prostate cancer have been found to have more bowel and bladder problems, sexual bother, and sexual dysfunction after treatment (Johnson et al., 2004; Schroeck et al., 2008), and studies have also indicated that Black men have poorer QOL than individuals from other racial/ethnic groups when diagnosed with prostate cancer (Chornoku et al., 2011; Jayadevappa, Chhatre, Wein, & Malkowicz, 2009; Matthews, Tejada, Johnson, Berbaum, & Manfredi, 2012; Schroeck et al., 2008). Thus, learning how Black men make their decisions may allow interventions to improve their decision-making and may improve their post-treatment QOL.

Finally, there is a need for more studies exploring prostate cancer treatment decision-making among Black men due to the dearth of qualitative literature on this subject (Chapple et al., 2002; Denberg, Melhado, & Steiner, 2006; Xu, Dailey, Egely, & Schwartz, 2012). Done well, qualitative studies can bring patients' experiences and voices into the mainstream discourse. Most participants enrolled in prostate cancer studies including studies investigating treatment decision-making were White. As a result, most evidence-based care studies effectively ignore people of color due to the emphasis on randomized controlled trials, which have few Black participants (Sue, 1999). There is a need for more qualitative studies among people of color to allow their experiences to be examined further from their perspective and in their own words (Frye & Challacombe, 2019; Graham & O'Connor, 2006). Additional qualitative research offers valuable information to providers caring for Black men that they can use to facilitate patient-centered care among this group of patients. Learning how Black men make their decisions may allow interventions to improve their decision-making and may improve their post-treatment QOL.

Purpose of the Study

This ethnographic study focused on the experiences of Black men after prostate cancer diagnosis. The purpose was to describe the treatment decision-making experiences of Black men diagnosed with prostate cancer to gain an understanding of how their culture affected their knowledge and perceptions of prostate cancer and its treatments. Patient, provider, or system level barriers that may have affected shared their decision-making processes were also explored. I chose Black men for this study because of their higher prostate cancer morbidity and mortality rates, and their poor treatment outcomes.

To decrease inequities among Black men, researchers must take a closer look at specific reasons for their treatment choices. Without additional research, we have imposed guidelines and policies on this group who are underrepresented in research. Additionally, understanding the cultural beliefs and values will increase cultural knowledge among providers. This will allow for a more trusting and respectful patient-provider relationship and follow through with treatment recommendations.

Research Questions

The overarching question, which I addressed in this study, was “What are the perceptions, meanings and experiences of Black men who receive treatment for prostate cancer in San Diego, California?” The primary reason for this descriptive ethnography and critical analysis was to give this group of Black men a voice. Examining the experiences of Black men with prostate cancer treatment decision-making can empower them to increase their involvement in the prostate cancer treatment process and alter the power dynamics of prostate cancer treatment decision-making. This will ultimately improve practice and help to decrease the inequities in prostate cancer treatment outcomes among this group of men.

The specific research questions were the following:

1. Who or what influenced their prostate cancer treatment decisions?
2. What difficulties, challenges or problems did they experience after treatment or on follow-up?
3. How did they describe patient-provider dynamics during the treatment decision-making process?

Background for the Problem: Prostate Cancer

Prostate cancer has been found to be influenced by a variety of factors such as culture, mistrust, racial bias, decreased educational levels, environment, income, limited access to care, lack of education and genetic factors (Armstrong et al., 2006; Barrington et al., 2015; Benkert et al., 2006; Betancourt & Maina, 2004; Gwede & McDermott, 2006). Historical and sociopolitical forces that affect Black people living in the United States shape most of these factors. These inequities will continue as long as sociocultural elements are excluded when guidelines are formulated from evidenced-based research primarily conducted with White men (Lee, Fitzpatrick, & Baik, 2013). Some researchers assert that the dearth of research studies involving people of color results in the inability to generalize most research findings. A group of researchers asked, “Can an evidence-based protocol with efficacy in a predominately racial/ethnic minority sample (i.e., Black or Korean) be considered EBP for the White population” (Lee et al., 2013, p. 265)? This would not be allowed to happen to the White majority, and it should not continue to happen to racial or ethnic minorities.

Prostate Cancer Prevalence

Prostate cancer is the second most commonly occurring cancer among men in the United States (excluding skin cancer), and the third leading cause of cancer death among in the United States (American Cancer Society, 2019b; Siegel, Ma, Zou, Jemal, 2014). As previously mentioned, the morbidity and mortality rates for prostate cancer among Black men are higher than in White, Hispanic, or Asian men (See Figure 1.), and Black men have higher morbidity rates for prostate cancer than other racial or ethnic groups worldwide (American Cancer Society, 2019a; Fitzmaurice et al., 2013; Tao, Shi, Wang,

& Zhang, 2015; Zullig et al., 2012). The prevalence of prostate cancer among Black men in the United States is 2.7%, and it is 1.7%, 1.3%, and 0.9% among Hispanic, White, and Asian/Pacific Islander men, respectively (National Cancer Institute, 2019).

Along with having a higher prevalence, prostate cancer also tends to be more aggressive in Black men than in White men. While some studies have found no differences in prostate cancer specific mortality rates between Black and White men (Sridhar, Masho, Adera, Ramakrishnan, & Roberts, 2010), many studies found that Black men tend to develop it at a younger age, have higher baseline prostate-specific antigen (PSA) values, higher overall cancer-specific mortality, higher rates of biochemical recurrence after treatment, and higher overall cancer-specific mortality (Chornouker et al., 2011; Schreiber et al., 2014). Studies have also shown that prostate cancer may start in similar ways among the racial groups but tends to progress faster among Blacks compared to Whites (McGinley, Tay, & Moul, 2016; Powell, Bock, Ruterbusch, & Sakr, 2009). As a result, it is reasonable to use caution when applying current guidelines to Black men (Sundi et al., 2013). In fact, researchers of one study recommended against the routine use of these guidelines even among those diagnosed with low risk prostate cancer after they found that Black patients with low risk prostate cancer who underwent active surveillance had worse outcomes related to having more aggressive cancer (Sundi et al., 2013).

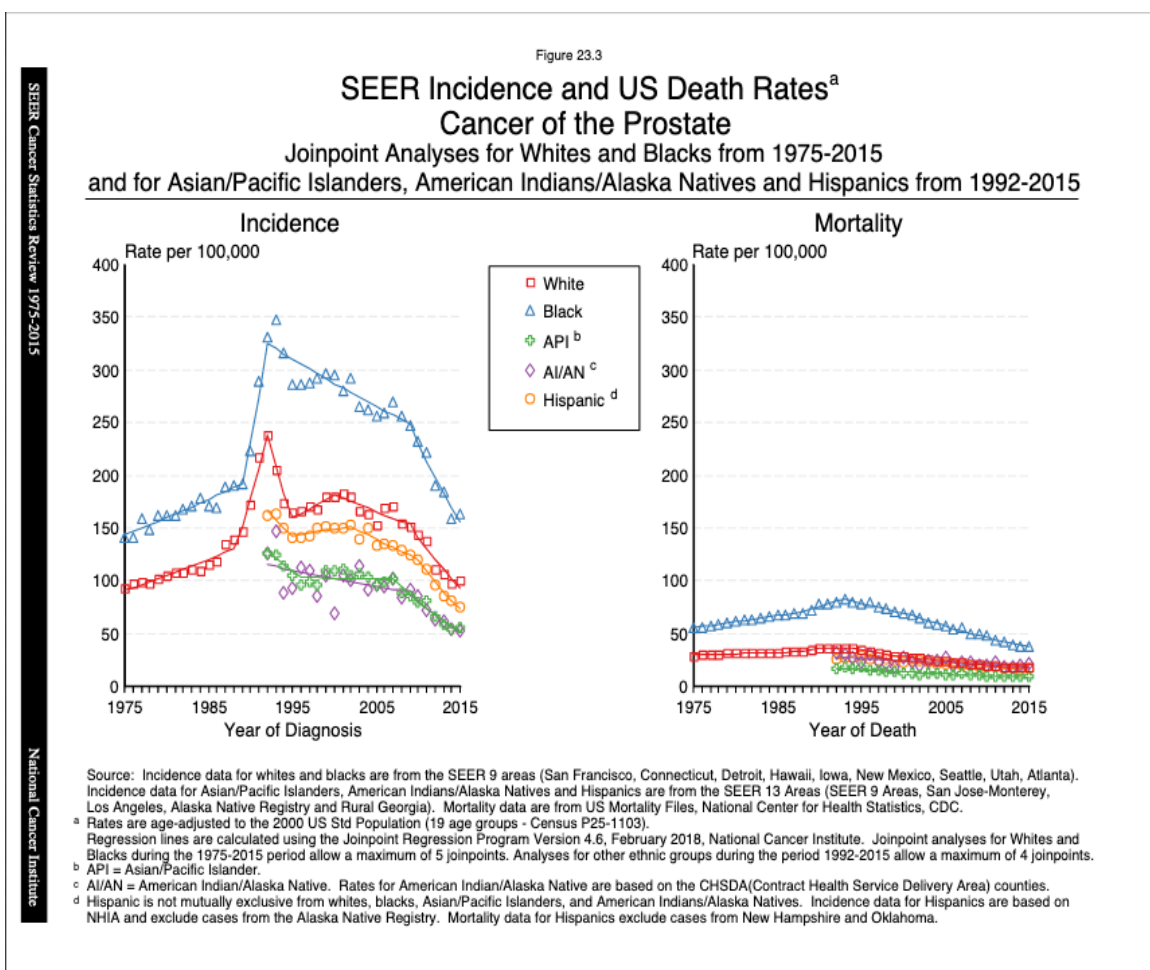


Figure 1. SEER incidence and U.S. death rates for prostate cancer by race (National Cancer Institute, 2018).

Prostate Cancer Screening, Treatment, Side Effects, and Controversies.

Prostate cancer is unique in that there is no consensus among healthcare providers and healthcare organizations about when and how long to screen, or which treatment strategy is optimal (Showalter, Mishra, & Bridges, 2015). Black race is a commonly accepted risk factor, along with advanced age and genetics (Jemal, Center, DeSantis, & Ward, 2010; National Cancer Institute, 2019; Nettey et al., 2018). Black American men have the highest rates of prostate cancer in the United States and throughout the world, while Asian men have the lowest rates (American Cancer Society, 2019a; Hsing, Tsao, &

Devesa, 2000; Odedina et al., 2009; Siegel et al., 2015). Hispanic men in the United States have a slightly lower incidence of prostate cancer than White men (Altekruse et al., 2010). Additionally, some studies have found that Black men chose less definitive treatments, such as watchful waiting, and tended to avoid surgery because they viewed it as too invasive.

Not only do Black men have an increased risk of developing prostate cancer, they tend to develop more aggressive forms of the disease, they have higher recurrence and mortality rates, and tend to be diagnosed at an earlier age than White men (Bigler, Pound, & Zhou, 2011; Moses, Chen, Sjoberg, Bernstein, & Touijer, 2014; Parker et al., 2011, Salami et al., 2007). Studies have also found that Black men have an increased risk of being diagnosed with advanced prostate cancer regardless of family history (Hamilton et al., 2007; Robbins, Yin, & Parikh-Patel, 2007).

The incidence of prostate cancer increases with age, and most cases occur in men over 65 years of age, with a peak incidence between the ages of 70-74. Having a positive family history doubles prostate cancer risk (Gwede & McDermott, 2006), and men whose brother or father had prostate cancer also have an increased risk of developing prostate cancer regardless of age (Bostwick et al., 2004; Tao et al., 2015). Interestingly, prostate cancer inequities between Black and White men seem to decrease as men get older, suggesting there should be an increased treatment focus on younger Black men (He & Mullins, 2017).

Several genes have been linked to prostate cancer (Schaid, 2004), and researchers have identified the mutations of the EphB2 gene in Black men with a family history of prostate cancer (Kittles et al., 2006; Robbins, Hooker, Kittles, & Carpten, 2011). In

addition, CYP3A4 genes are associated with the development and aggressiveness of prostate cancer, and are more prevalent among Black men (Powell et al., 2010; Powell et al., 2013).

Other possible risk factors that researchers have explored are having a vasectomy, dietary factors, obesity, exercise habits, prostatitis, infection, and socioeconomic status (Barrington et al., 2015; Gwede & McDermott, 2006). Interestingly, vasectomy was thought to be a possible risk factor for prostate cancer, but studies have found no association between vasectomy and prostate cancer risk in patients referred for prostate biopsy (Bhindi et al., 2017; Chacko, Zafar, McCallum, & Terris, 2002). Red meat consumption may be a risk factor in Black men, but not in White men. Researchers theorized that Black men had a higher intake of processed meats and more saturated fats (Jones et al., 2007; McIntosh, 1997; Rohrmann et al., 2007). Lack of screening, socioeconomic factors such the lack of educational opportunities, high levels of stress, and exposure to environmental toxins have also been implicated (Armstrong et al., 2006; Bell & Duffy, 2009; Benkert et al., 2006; Betancourt & Maina, 2004; Carpenter et al., 2009; Cheatham et al., 2008; Halbert et al., 2009; Halbert, Armstrong, Gandy, & Shaker, 2006; Jones et al., 2006; Shi, 2010; Underwood et al., 2004).

More research is needed to explore the role of diet, stress, and exercise on prostate cancer development and treatment. Some promising studies found that the use of lifestyle modifications which included a plant-based diet low in fat and refined carbohydrates, moderate exercise, and improved social and community support resulted in decreased PSA levels, suppression of activity in genes that cause oxidative stress, chronic

inflammation, an increase in the activity of protective genes, and in 5 years increased telomere length (Ornish et al., 2005; Ornish et al., 2008; Ornish et al., 2013).

Infection and inflammation have been linked to several types of cancer (Maitland & Collins, 2008), and infection in the form of acute or chronic bacterial prostatitis may be associated with prostate cancer. Sarma et al. (2006) theorized that prostate cancer may be linked to sexually transmitted infections in Black men compared to White men, but the data were not very convincing. Numerous research studies have been conducted on other prostate cancer risk factors such as health insurance, smoking and geographic location, but there have been conflicting findings (Antwi, Tucker, Coker, & Fleming, 2013).

Screening. There has been a substantial increase in the detection of prostate cancer since the introduction of PSA testing (Amling, 2006; Negoita et al., 2018). Some studies found that early detection via screening was important (Jones, Steeves, & Williams, 2007; Moses et al., 2014). However, additional studies had equivocal findings on the benefits of prostate cancer screening (Moyer & U.S. Preventive Services Task Force, 2012; U.S. Preventive Services Task Force, 2008). The lack of consensus among providers about the effectiveness of treatment options, such as prostatectomy, different types of radiation and active surveillance, along with the wide range of adverse treatment side effects, such as bladder and bowel problems, erectile dysfunction and anxiety contribute to the complexities of treatment (Downs et al., 2003; Hall, Boyd, Lippert, & Theodorescu, 2003; Hu et al., 2009; Litwin et al., 2007; Lu-Yao et al., 2009; National Comprehensive Cancer Network, 2015; Potosky et al., 2000). Regardless of screening recommendations, people who come from disadvantaged socioeconomic backgrounds, and those with lower educational attainment tend to undergo less screening for cancer

and preventable illnesses (Thorpe, Bowie, Wilson-Frederick, Coa, & Laveist, 2013). These factors along with cultural differences and decreased access to healthcare may have resulted in less screening for prostate cancer than White men (Jones et al., 2007).

Studies have shown that routine screening for prostate cancer can reduce mortality rates among Black men by allowing for diagnosis in its earlier stages (Carpenter et al., 2010; Hoffman et al., 2003; Odedina et al., 2004). When Black men received information about prostate cancer screening from their providers or from public health outreach programs, their screening rates were similar to the screening rates of White men (Ross, Powe, Taylor, & Howard, 2008; Sellers, Bonham, Neighbors, & Amell, 2009; Thorpe et al., 2013). Yet there is a growing movement against routine PSA screening. The current prostate cancer screening guidelines advise against routine PSA screening since long-term studies have also found that prostate cancer is being over diagnosed and over treated since the treatments do not prolong life (Fowler et al., 2011; Xu et al., 2012). This shift away from screening is primarily the result of data obtained from a meta-analysis (Ilic, Neuberger, Djulbegovic, & Dahm, 2013), and two large, long-term randomized studies, the Prostate, Lung, Colorectal, and Ovarian (PLCO) Screening Trial and the European Randomized Study of Screening for Prostate Cancer. The National Cancer Institute conducted the PLCO. Both the meta-analysis and the PLCO study found no significant effect of PSA screening on prostate cancer mortality, while the European trial found a minimal effect of PSA screening on prostate cancer mortality (Carpenter et al., 2010; Ilic et al., 2013). It is important to note that there were few Black participants in these studies; hence, few meta-analyses of prostate cancer screening

include studies with sufficient numbers of Black men for reliable conclusions (Bibbins-Domingo, Grossman, & Curry, S. J., 2017).

Some researchers recommend separate screening guidelines for Black men since the two studies upon which the current USPSTF guidelines are based had very few Black participants. Black participants comprised only 4% of the population in the U.S. study. The European study was conducted in countries with very few Blacks, and the race of the participants was not mentioned (Carpenter et al., 2010; Reddy et al., 2018; Shenoy, Packianathan, Chen, & Vijayakumar, 2016).

The American Urological Association's (AUA) most recent guideline recommends against routine screening for men between the ages of 40 to 54 in men with average risk for prostate cancer (American Urological Association, 2017). According to the AUA, the high-risk group includes Black men, men with a prostate cancer family history in several generations and/or men with a family member(s) diagnosed below 55 years of age have a greater than average risk (American Urological Association, 2017). However, five of the most influential medical and public health organizations (the American College of Physicians, the American Society of Clinical Oncology, the NCCN, the American Cancer Society, and the American College of Preventative Medicine) endorse limited prostate cancer screening based upon different risk parameters. The U.S. Preventative Services Task Force encourages the discontinuation prostate cancer screening in community and workplace settings, and strongly encourages the use of shared patient-provider decision-making about the benefits and risks by physicians who insist on screening their patients for Prostate cancer. These multiple recommendations can be confusing to both providers and patients.

When the United States Preventative Services Task Force (USPSTF) initially recommended against routine screening of prostate cancer, there was no mention of Black men. However, in 2017, they updated their recommendations by encouraging an individualized approach with Black men regarding whether to screen using shared decision-making (Grossman et al., 2018). Now, the American College of Physicians (ACP), American Cancer Society (ACS), American Urological Association (AUA), U.S. Preventive Services Task Force (USPSTF), and American Society of Clinical Oncology (ASCO) all recommend using informed decision-making with patients when discussing prostate cancer screening options. This could be a difficult endeavor for Black men based upon their history medical mistrust and perceived racism (Armstrong et al., 2006; LaVeist, Isaac, & Williams, 2009; Leinwand, Gabrielson, Krane, & Silberstein, 2016; Song et al., 2014; Wilkinson, List, Sinner, Dai, & Chodak, 2003). Additionally, an individualized approach requires effective patient-provider communication, and is affected by a variety of factors such as patient preferences, level of understanding, educational level, perceptions of both patient and provider, noncompliance, and decreased satisfaction (Cooper et al., 2004; Penner, Albrecht, Coleman, & Norton, 2007; Penner et al., 2010; Siminoff, Graham, & Gordon; 2006). Earlier screening along with definitive treatment (prostatectomy and radiation) may reduce prostate cancer inequities among Black men (Moses et al., 2014). However, other important factors such as culture and beliefs must be examined since the reasons for these persistent racial inequities among Black men are unknown (Sanchez-Ortiz et al., 2006).

While earlier screening and definitive treatment (prostatectomy and radiation) have reduced prostate cancer inequities in Black men (Moses et al., (2014), other factors

such as cultural traditions and healthcare experiences must be examined to determine the reasons for these persistent racial inequities (Bianco et al., 2002; Jones et al., 2008; Moses et al., 2014; Sanchez-Ortiz et al., 2006).

Treatment. Black American men experience not only inequities in the prevalence and screening of prostate cancer; they also encounter inequities in treatment and outcomes of treatment. The most common types of prostate cancer treatment are surgery (prostatectomy) radiation (internal radioactive seed or external) and active surveillance/watchful waiting (American Urological Association, 2017; National Cancer Institute, 2019). Other less common treatment options include cryosurgery, high intensity focused ultrasound, and focal therapy (American Urological Association, 2017).

Treatment of prostate cancer tends to be individualized, and factors such as age and comorbidities help to determine treatment. Active surveillance is often recommended in men diagnosed with low risk prostate cancer due to its slow progression (Carter et al., 2013; National Comprehensive Cancer Network, 2015). However, some studies have found that Black men who ignored treatment recommendations and underwent surgery despite having very low risk prostate cancer were found to have higher risk disease as indicated by more aggressive pathology and by having surgical margins positive for cancer (Ha et al., 2013; Sundi et al., 2014). In contrast, some studies have found similar pathologic outcomes between Black men and White men (Leapman et al., 2016). Some studies found that Black men tended to underutilize the two definitive treatments for prostate cancer, radiation, and surgery because they consider them to be too invasive (Barocas & Penson, 2010; Harlan et al., 2001; Hoffman et al., 2003; Kim et al., 2014; Morris, Snipes, Schlag, & Wright, 1999; Underwood et al., 2004; Wu et al., 2005), while

other studies indicated that Black men tended to choose more definitive treatment more often than men from other racial/ethnic groups regardless of socioeconomic status (Krupski et al., 2005; Schwartz et al., 2009; Shavers et al., 2004; Xu et al., 2012).

However, when Black men choose active surveillance or watchful waiting, they may have poorer outcomes due to less frequent follow-up (Shavers et al., 2004; Steenland et al., 2011).

Like prostate cancer screening, there is no consensus among clinicians regarding the best treatment strategies (National Comprehensive Cancer Network, 2015; O'Rourke, 2007; Sanda et al., 2008). This lack of agreement among healthcare providers and medical organizations can cause confusion among patients. Even when diagnosed with low-risk prostate cancer, Black men who undergo surgery have higher rates of positive margins (remaining cancer in the edges of the prostatic tissue after prostatectomy, which increases the risk for recurrence) and biochemical recurrence than White men (Amling et al., 2004; Faisal et al., 2014; Hamilton et al., 2007). Post prostatectomy pathology results have also found that anterior tumors were more common among Black men than White men, resulting in lack of sampling during prostate biopsy (Sundi et al., 2014). Black men typically have higher rates of obesity, which research has linked to increased aggressiveness and increased recurrence of prostate cancer (Barrington et al; 2015; Caire, Sun, Polascik, Albala, & Moul 2010). Black men often present with more co-morbidities than White men, and this results in higher mortality rates (Holmes et al., 2009). Since fewer than 25% of men diagnosed with prostate cancer die from the disease (Hoffman et al., 2015), and definitive treatment does not prolong life (Fowler et al., 2011; National Comprehensive Cancer Network, 2015), treatment is often not recommended for men

over 70 years of age, especially if they have multiple co-morbidities (Hoffman et al., 2015).

Specialty bias also affects prostate cancer treatment recommendations. Specialists who treat prostate cancer tend to recommend the treatment modality in which they were trained (i.e., urologists recommend surgery and radiation oncologist recommend radiation). As a result, many men report not receiving information about all available options (Chapple et al., 2002; Jang et al., 2010; Ramsey et al., 2011; O'Rourke, 1999). When men receive prostate cancer treatment information from urologists, they often believe that surgery is the only way to cure the cancer (O'Rourke, 1999). The therapeutic modality of the treating provider is usually what is chosen, with urologists recommending surgery and oncologists recommending radiation (Jang et al., 2010; Sommers et al., 2008). Furthermore, studies have shown that when patients seek a second opinion from urologists, all available treatments are usually not discussed, and patients are usually advised to have surgery (Ramsey et al., 2011). Since alternative options are often not presented, men diagnosed with prostate cancer may not have the complete capacity to make an informed decision.

Even with inconsistent findings and continued prostate cancer inequities among Black men, the National Comprehensive Cancer Network guidelines and other recent studies continue to recommend active surveillance for the treatment of low risk (Gleason 6) prostate cancer in Black men despite evidence that their risk of dying is double that of men from other races (Leinwand et al., 2016; Mahal, Berman, Taplin, & Huang, 2018; National Comprehensive Cancer Network, 2015). Black men tend to put the needs of their families before their own needs, and often prefer to cope with the diagnosis of

prostate cancer on their own (Blocker et al., 2006; Cheatham et al., 2008; Dimah & Dimah, 2010; Kazer et al., 2011). As a result, they may not seek immediate care, and when they do seek care, the wide variety of treatment choices hinders the treatment decision-making process (Cox & Amling, 2008; Schymura et al., 2010; Showalter et al., 2015). Additionally, studies have found that Black men who undergo prostatectomy for prostate cancer had worse bowel function and better sexual functioning post-prostatectomy than White men, as well as better bowel function after radiation treatment than White men (Orom et al., 2017). Other studies suggested that Black men have the most urinary bother after they underwent either surgery or radiation, while other studies suggested that there were no inequities in bowel or bladder function (Bryant et al., 2016). The exact reasons are not known (Orom et al., 2017).

This lack of consensus, the potential for unforeseen side effects, and the individualized nature of treatment can cause further indecision and anxiety about treatment choices before treatment and even after being treated. Feelings of uncertainty and doubt about choosing the “right” treatment can also increase (Clark & Talcott, 2006; Goh et al., 2012; Wilt et al., 2008). Uncertainty often leads to decisional regret, especially when side effects of prostate cancer treatment develop. Decisional regret can occur early in the treatment process and has been found to continue for several years (Holmboe & Concato, 2000; Morris et al., 2015).

The elimination of health inequities is the major goal of the Centers for Disease Control and Prevention’s (CDC), Healthy People 2020 campaign, which started 20 years ago (Centers for Disease Control and Prevention, 2013; Healthy People 2000, n.d.; Healthy People 2010, n.d.; Healthy People 2020, n.d.). Despite their efforts, health and

healthcare inequities within vulnerable populations persist. The major goal of Healthy People 2020 (n.d.) is to improve the health for all Americans. The CDC has also stressed the importance of informed health decision-making (U.S. Department of Health and Human Services, 2015).

Theoretical Framework

I chose Powers and Faden's (2006) social justice theory because it connects racial inequities and social determinants to health and healthcare. The social justice perspective allows researchers to understand how racial inequities and social determinants such as socioeconomic status and education affect health and healthcare treatment choices of Black Americans (Dailey, 2008). Everyone in society would benefit if social justice were institutionalized (Capeheart & Milovanovic, 2007; Rawls, 1971/2005). Unfortunately, this is not the case. Black people and other vulnerable groups will continue to experience inequities as long as they are measured according to a White, middle class standard (Boutain, 2005). This can be conceptualized as the "normalization of social injustice," and it tends to "make discrimination invisible" (Giddings, 2005). Social justice is a concept shaped by history and politics in which there should be fairness and balance in the allocation of distribution societal goods, services such as healthcare, education, and in burdens such as crime (Capeheart & Milovanovic, 2007). Social justice theories acknowledge that some social groups bear the burden of unequal treatment, and recognize that racial inequity is a form of social injustice (Boutain, 2005). These theories are especially relevant to when guiding research of disenfranchised groups such as Black Americans.

John Rawls and Martha Nussbaum are prominent social justice theorists. Rawls is perhaps the best known, and many current social justice theories originate from his ideas. He believed in the right to fair and equitable inclusion in educational and economic opportunities (Rawls, 2003, 1971/2005). Nussbaum (1992) and Amartya Sen (1995) who has a Nobel laureate in economic science have written about government's role in ensuring social justice. Powers and Faden's (2006) social justice theory is not as well-known. However, I chose this theory because it emphasizes human well-being and concentrates on the need for social justice in healthcare.

Madison Powers and Ruth Faden (2006) are bioethicists who developed a six-dimensional theory of social justice. Their theory differs from Sen (1995) and Nussbaum (1992) because they are concerned with the actuality of well-being as an essential part of social justice, not just the possibility of it (Powers & Faden, 2006). Although justice and health policy implementation are addressed in bioethics, the primary emphasis is on the appropriate provision and distribution of medical care (Powers & Faden, 2006). Powers and Faden developed this theory because they believed that it is essential for researchers to look outside of the realm of medicine to understand inequities in the access and availability of healthcare. In fact, one of the primary goals for Healthy People 2020 includes creating "social and physical environments that promote good health for all" (The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020, 2008, p. 6). This includes opportunities for jobs, safe neighborhoods, and good schools. Powers and Faden (2006) asserted that human well-being, is the "primary objective" of social justice, and it is at the center of their theory.

Well-being “is a necessary condition for a decent life” (Powers & Faden, 2006, p. 15). It is the target that institutions and governments should aim for since their policies and practices affect well-being (Powers & Faden, 2006). Powers and Faden (2006) also asserted that guaranteed healthcare access for all people is a requirement for justice and it cannot be achieved under adverse social conditions. Powers and Faden did not intend to develop an “ideal” theory and they believe that it is more of a framework used to evaluate justice than a theory. It moves past questions of distributive justice and focuses on which inequities produce the worst societal consequences (Powers & Faden, 2006). Powers and Faden described two aims that must be achieved for social justice to occur. These aims are the improvement of well-being, and the prevention of “systemic patterns of disadvantage” that negatively affect well-being (Powers & Faden, 2006, p. 9). Failure to do this results in what Madison (2012) called “narrow perception, limited modes of understanding, and uncritical thinking, which diminish the capacity to envision alternative life possibilities.” (p. 6)

For this model, human well-being consists of six basic dimensions. The dimensions are health, personal security, reasoning, respect, attachment, and self-determination. For social justice to occur, each dimension must be met at a “sufficient level” to live a decent life (Powers & Faden, 2006, p. 16). This framework was most relevant for my exploration of the experience of shared decision-making among Black men diagnosed with prostate cancer. Health and health inequities such as those found in Black men diagnosed with prostate cancer will continue if we continue to focus primarily on medical causes. It is useful here to clarify the definitions and other key terms in this study (Table 1).

Table 1

Definition of Key Terms

Terms	Definitions
Active Participation	A process of medical decision-making where patients play a collaborative (active) role. It is often used interchangeably with shared decision-making (Fraenkel & McGraw, 2007, p. 614).
Active Surveillance	A disease management strategy that delays curative treatment until it is warranted based upon defined indicators of disease progression (Ganz et al., 2012, p.592).
African American	“Refers to a person having origins in any of the Black racial groups of Africa. (U.S. Census Bureau, 2011, p.2).
Culture	“A set of guidelines (both explicit and implicit) that individuals inherit as members of a particular society, and that tell them how to view the world, how to experience it emotionally, and how to behave in relation to other people, to supernatural forces or gods and to the natural environment. It also provides them with a way of transmitting these guidelines to the next generation-by the use of

	symbols, language, art, and rituals (Helman, 2007, p.2).
Cultural Humility	“A lifelong commitment to self-evaluation and critique, to redressing the power imbalances in the physician-patient dynamic, and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations” (Tervalon & Murray-Garcia, 1998, p. 117).
Decisional Regret	“Remorse or distress over a decision” (Brehaut, 2003, p. 282).
Definitive Therapy/Treatment	Curative therapy that “includes radical prostatectomy (RP), external beam radiation therapy (EBRT) and brachytherapy (BT)” (Jang, et al., 2017, p. 1827).
Discrimination	“Unfair or unjustified group-based difference in behavior that systematically disadvantages members of another group (Dovidio et al., 2008, 179).
Discrimination in Healthcare	When “differences in healthcare occur in the context of broader historic and contemporary social and economic inequality and persistent racial and ethnic discrimination in many sectors of American life” (Nelson, 2002, p. 666).

Ethnicity	“Clusters of people who have common culture traits that they distinguish from those of other people” (Smedley & Smedley, 2005).
Equal Access Healthcare System	A healthcare system in which “reduce financial and nonfinancial barrier to care “(Wong, 2019, p. 99).
Health Care Inequities	“Patterns of bias and inequities in health and healthcare “(Institute of Medicine, 2003, p. 505).
Health Equity	The realization by ALL people of the highest attainable level of health (Jones, 2009, slide 100).
Health Literacy	Skills “that people use to realize their potential in health situations” (CDC, 2016).
Intersectionality	The ways in which “individuals are simultaneously situated socially in terms of their gender, race, sexuality, and class (among other things) and that these structural dimensions define social hierarchies (of status and power) that operate together in complex ways that cannot be accurately understood in isolation” (Curtin, Stewart, & Cole, 2015, p. 513).
Oppression	The structural arrangement by which resources, power, and privileges are organized in a way that creates unequal access to the very things we need to be personally, financially, and professionally

successful in life. Oppression is referred to as “structural” because the inequities are not at all random. Rather the resources, power, and privileges that we have access to as individuals depend largely on our membership in social groups. The fabric of oppression is a systematic phenomenon that creates some groups that are privileged by oppression and other groups that are targeted by it. It is possible to be part of a privileged group and benefit from that system of privileges without ever behaving in a way that is mean, prejudiced, or hateful. Conversely, one can also be part of a targeted group without ever experiencing a hateful act (Holtzman & Sharpe, 2013, p.21).

Patient Centered Care

Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions (Institute of Medicine, 2001, p.6).

Patient Preferences

Patients’ choices regarding healthcare that are based on a full and accurate understanding of treatment options (Institute of Medicine, 2003, p. 4).

Prejudice	“Reflects a general negative evaluation or orientation to a group or a member of a group” (Dovidio et al., 2008, p.478).
Prostate Cancer	Cancer that “forms in the tissues of the prostate” (National Cancer Institute, 2017, para. 2).
Prostate Cancer-Low Risk	“Patients with clinical T1 to T2a, Grade Group 1, and serum PSA level <10 ng/mL” (National Comprehensive Cancer Network, 2019, p. MS-48).
Race	The social interpretation of how we look (Jones, 2009, slide 49).
Racial Concordance	“Having a shared identity between a physician and a patient regarding their race” (Shen et al, 2018, p. 118).
Racism	“A system of structuring opportunity and assigning value based on the social interpretation of how we look” (Jones, 2009, slide 52).
Racism (Aversive)	“Characterizes the biases of those who are politically liberal and openly endorse non-prejudices views, but whose unconscious negative feelings and beliefs get expressed in subtle, indirect, and often rationalizable ways” (Pearson, Dovidio, & Gaertner, 2009, p. 317).

Racism (Institutionalized)	“Differential access to the goods, services, and opportunities of society by ‘race’” (Jones, 2009, slide 87).
Racism (Symbolic)	“A set of ideas that (a) racial discrimination is no longer a serious obstacle to blacks’ prospects for a good life, so that (b) blacks’ continuing disadvantages are largely due to their unwillingness to work hard enough. As a result, both their (c) continuing demands, and (d) increased advantages are unwarranted” (Tarman & Sears, 2005, p. 733).
Shared Decision-Making	“Medical treatment decision-making “where patients play an active role” (Fraenkel & McGraw, 2007, p.614).
Social Justice	“Dimensions of human well-being that are of special moral urgency because they matter centrally to everyone, whatever the particular life plans and aims each has” (Powers & Faden, 2006, p.15).
Stereotype	“The association or attribution of specific characteristics to a group and its members” (Dovidio et al., 2008, p. 478).
Violence, Physical	“The intentional use of physical force or power, threatened or actual, against oneself, another

person, or against a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation” (World Health Organization, 2002, p. 4).

Violence, Symbolic

“Any incidence in which a person or persons are labeled as inferior by those in the dominant society and are rendered voiceless” (Bourdieu, 1999/2001).

Watchful Waiting

“Palliative treatment initiated when the patient develops symptoms of the disease” (Ganz et al., 2012, p.592).

Assumptions for the Study

My review of the literature and my experiences as a nurse practitioner who treats Black men diagnosed with prostate cancer led me to the following assumptions:

- Black men are the group most affected by prostate cancer.
- Most research exploring prostate cancer have few Black participants
- Poor prostate cancer outcomes and low study participation has been normalized.

Scope and Delimitations

This study only focused on treatment decision-making among a sample of men who self-identified themselves as Black and who sought treatment for prostate cancer in San Diego, California. Exclusion of other races allowed for the exploration of cultural patterns unique to Black men.

Limitations

One limitation of this qualitative study was that the findings cannot be generalized to all Black men, even those whose sociodemographic profiles resembled my sample. Second, there was a potential for loss of confidentiality when I attended public gatherings, such as churches or picnics. Additionally, there was a possibility of researcher bias since I work with Black men diagnosed with prostate cancer. Researcher bias and reactivity are two common threats to any study's validity (Maxwell, 2005). To reduce and manage bias, I have acknowledged my personal beliefs. Reactivity can also affect study findings. It is the effect that the researcher's presence has on the way participants respond (Maxwell, 2005). It can be difficult to control because responses could be influenced by the researcher or peers. Using an interview tool helped to reduce reactivity by maintaining consistency. Trust between the researcher and participants is essential for credibility (Creswell, 2018). To minimize this potential limitation, I had frequent encounters and interviewed the participants at length, unrushed (Creswell, 2018). I also utilized respondent validation, collected rich data, debriefed with qualitative mentors, and utilized triangulation to ensure validity (Creswell, 2018; Maxwell, 2005).

Significance

Cultural differences between patients and providers should not be an excuse for delivering suboptimal care (Cheatham et al., 2008). Knowing why Black men choose their prostate cancer treatments could result in the identification of potential cultural barriers to shared decision-making. This would allow for new interventions and the development or modification of policies and practices, which could possibly improve prostate cancer outcomes. Findings from this study add to the knowledge in an area that

has not been adequately studied. There is a relative lack of racial and ethnic diversity among healthcare providers in the United States. This has led to patient-provider racial discordance, which can result in suboptimal treatment outcomes due to cultural imposition and differences in health beliefs and values (Wright, 2013). Therefore, information from this study could help to improve interactions between Black men and their providers by increasing provider awareness of cultural gaps in healthcare values that exist between men diagnosed with prostate cancer veterans and their providers.

Summary

Black men continue to have the highest morbidity and mortality rates for prostate cancer in the United States. In Chapter 2, a critical review of the extant literature on prostate cancer in Black men, the culture and health beliefs of Black men, theoretical framework, and the qualitative research method will be presented. The methodology to address the research questions will be described in Chapter 3.

CHAPTER 2: REVIEW OF LITERATURE

“Every disease has two causes. The first is pathophysiological: the second, political” (Spanish neuroscientist and Nobel Prize winner Santiago Ramon y Cajal, 1899)

Introduction

The purpose of this chapter is to provide an overview and critical analysis of the literature surrounding prostate cancer treatment decision-making among Black men. The content is organized to address the following areas: the effect of race and racism among Black Americans, a review of prostate cancer treatment decision-making studies among Black men, and the application of Power and Faden’s theory to prostate cancer treatment decision-making among Black men.

The theoretical framework and qualitative tradition for methods will also be presented in this chapter. The major databases of CINAHL, Medline, and PubMed, PsycInfo were searched using the following keywords and terms: *treatment/clinical decision-making, shared decision-making, treatment preferences, racial inequities, prostate cancer, prostate neoplasm, prostate adenocarcinoma, African American/Black men*. This review will include studies from peer-reviewed journals published between 1998 and 2019 that reported data about prostate cancer treatment among Black men.

The Effect of Race, Racism on Black Americans

Black Americans comprise 12.9% of the total U.S. population and are considered to be one of its many vulnerable groups. Individuals are considered to be vulnerable if they belong to a group that disproportionately experiences poor QOL, and inequities in health. Uninsured people, non-English speakers, mentally and physically disabled,

prisoners, the elderly, and people of color are some examples of groups who fit in this category (Shi, 2010). Reasons for this vulnerability include high poverty levels, high unemployment levels and high rates of no insurance coverage (Shi, 2010). Adverse social conditions such as high levels of violence, incarceration, chronic disease, mental illness, and substance abuse also plague the Black community (Shi, 2010).

Black Americans have the highest poverty and unemployment rates in the U.S. (Shi, 2010; U.S. Census Bureau, 2015). The “War on Drugs” and “Stop and Frisk” programs resulted in mass incarceration of people of color. Zero tolerance policies in schools also disproportionately affect children of color. Expelling children of color for minor infractions has become commonplace and is now referred to as the “school to prison pipeline” (American Civil Liberties Union, n.d.). These policies have further decimated the health and well-being of the Black community by criminalizing entire communities. Some call this phenomenon the “New Jim Crow” because it is seen by many as a way of reining in people of color (Alexander, 2012; Drug Policy Alliance, n.d.).

Research has shown that Black people are also overrepresented in occupations and neighborhoods where exposure to toxic substances is common, and this maybe one of the many reasons that the average lifespan among Blacks in the United States is lower than other racial/ethnic groups (Arias, 2014). In fact, The Institute of Medicine (2003) identified racism as a major contributing factor to current state of poor health among people of color. Penner et al. (2007) found that most Black people (75%) do not see providers of the same race (racially discordant). This contributes to mistrust and poor

patient-provider relationships (Cooper et al., 2004; Penner et al., 2007; Penner et al., 2010; Siminoff et al., 2006).

Regardless of the persistent problems that besiege Black communities, many White Americans believe that racism is no longer a problem, and believe we live in a colorblind society since we have had a Black man previously elected as the president (Bonilla-Silva, 2010). Furthermore, many policymakers assert that everyone can achieve the American Dream if he or she works hard enough. The evidence presented by the media show the successful Black people in sports and entertainment, while the news media focuses on crimes committed by people of color. Sadly, most Whites only experience Blacks in the workplace, and they are usually not their colleagues, neighbors, or friends (Bonilla-Silva, 2010).

Claudia Rankin (2014, p. 63) wrote, “The world is wrong. You can’t put the past behind you. It’s buried in you; it’s turned your flesh into its own cupboard.” The type of racism that Black people experience today is often very subtle and is demonstrated by avoidance, indifference, and exclusion (Dovidio et al., 2008). This makes it more challenging to identify and fight (Sullivan, 2006). The concept of racial color blindness essentially erases all other races and their history except for the White race, and ignores the pain and distress of invisibility. As Hirsch (2018, para. 1) so eloquently stated,

To be black, in a society that invented race for the specific purpose of dehumanizing people who are black, and then invented an equally formidable system of denial, is to carry the burden of history that others would rather forget.

Lawmakers and courts have begun to dismantle the very laws that protect not only Blacks, but also other vulnerable groups (Woods, Montgomery, Belliard, Ramirez-

Johnson, & Wilson, 2004). To fully understand the reasons behind health inequities among Black Americans, the concept of race and racism must be explored. No study on Blacks in the United States can be complete without examining these concepts.

Race and Racism-Historical Aspects

The common socio-cultural identity and intersectionality of Black people have been shaped by capitalistic endeavors of slavery, colonialism, and imperialism (Leone, LaRoche, & Babiarz, 2005). This changing identity began in 1619 when the first African slaves arrived in Jamestown, Virginia. Their shared history of slavery, segregation, and racial persecution has influenced their family life, spirituality, food, arts, literature, social status, political status, economic status, and health status.

Black Americans have endured years of social, economic oppression, and medical mistreatment, while White Americans were the recipients of many government-sponsored programs that benefitted them financially. According to Katznelson (2005), this was when affirmative action was White. When slaves were imported from Africa to America, they took the place of European indentured servants who then became their overseers (Adelman & Herbes-Sommers, 2003). When slavery was abolished, Southern Blacks never received the land promised as reparations for slavery as part of a plan developed by General Sherman, but the U.S. Government reimbursed plantation owners up to \$300 for each piece of property (slave) lost after emancipation (Adelman & Herbes-Sommers, 2003). The approximate profit to Whites from free slavery labor is \$1 trillion (Adelman & Herbes-Sommers, 2003).

During the Great Depression, times were hard for most Americans. The passage of Franklin Roosevelt's New Deal in 1935 allowed economic recovery for White

Americans and allowed many to enter the middle class. In 1944, the World War II GI Bill was enacted and this bill had “more impact on the American way of life than any law since the Homestead Act of 1862” (U.S. Department of Veterans Affairs, 2014, para. 10). Conversely, most Blacks did not fare well during those times. Blacks were often terrorized if they owned homes or businesses. In the early 1900s, entire Black neighborhoods, such as Greenwood in Tulsa, Oklahoma and Rosewood, Florida were destroyed and innocent people were killed by mobs of Whites for being too prosperous. In fact, innocent Blacks were regularly snatched from their homes and lynched or burned in public displays to terrorize and control Blacks. These events were also forums of entertainment for some White families who travelled for miles to watch (Adelman & Herbes-Sommers, 2003; Bennett, 1993).

The Jim Crow Laws were established in the late 19th and 20th centuries. These laws restricted where Blacks could live, eat, work, attend school, or even receive healthcare, and they were not overturned in many states until the 1960s (Adelman & Herbes-Sommers, 2003; Bennett, 1993). As a result, few Blacks owned land or received assistance from the government. The Civil Rights Movement in the 1960s increased opportunities for Black people by outlawing barriers to voting based on race and by allowing them to attend previously segregated universities (Bennett, 1993).

Economic inequities that were caused by slavery and discrimination are often ignored in U.S. History. In fact, teaching it is sometimes discouraged. Lawmakers in Oklahoma recently attempted to pass a law banning state funds for teaching Advanced Placement (AP) U.S. History and to restrict the content of what was taught (Oklahoma HB1380: 2016: Regular Session, n.d.). The sponsors of HB 1380 argued recent changes

in the curriculum developed by the College Board, including discourse on oppression of disenfranchised groups due to race, ethnicity, or gender, made America look bad.

Fortunately, it died in chamber. One does not need to rewrite history to know that racial and economic prejudice and oppression have existed and continue to exist in the United States. In 2014, the United Nations Human Rights Committee found 25 violations committed by the United States, such as racial inequities in the criminal justice system, excessive use of police force, and racial profiling, to name a few (United Nations Human Rights Committee, 2014).

Condemnation of the United States for racial injustice is not new. In 1954, the U.S. Government's treatment of Black Americans was publicly challenged by Swedish economist Gunnar Myrdal when he published his study, *An American Dilemma: The Negro Problem and Modern Democracy*, sponsored by the Carnegie Corporation Foundation (Byrd, 2000). He challenged the inhumane treatment of Blacks as being the opposite of the fair and equal treatment that American promised for all of its citizens (Myrdal, 1944). Myrdal (1944) later became a Nobel laureate in Economic Sciences in 1974.

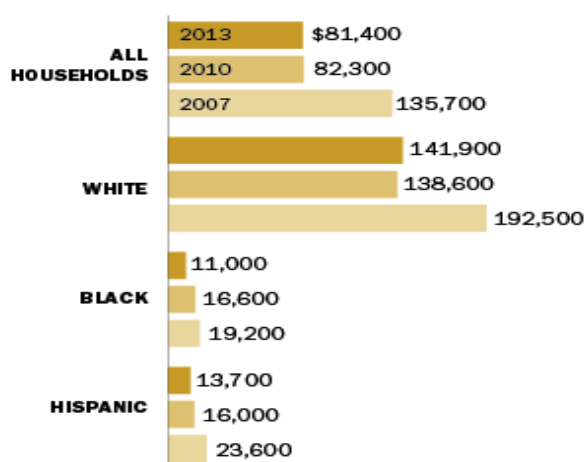
Long before Myrdal (1944) published his findings, Alexis De Tocqueville, a Frenchman who visited America in the 19th century, challenged that the proposition in the Declaration of Independence that "all men are created equal." Tocqueville asserted that the race problem and social inequality would cause problems for America (Tocqueville, 2003). World-renowned Black sociologist, W.E.B. DuBois, also cautioned that there would be a race problem in the 20th century (Du Bois, 1903/1994). He initially began to study and write about Black people because he thought that the problem of racism could

be solved if Whites had a better understanding of Black people. He believed that and racism was responsible for the poor socioeconomic conditions of Black people (Du Bois, 1903/1994). Long before Dovidio (2004) developed the term “aversive racism,” Du Bois realized that much racism was unconscious. However, Du Bois changed his mind about ending racism by the end of the World War I due to the continued racism that Black soldiers endured. He asserted that White people had a propensity to control, dominate, and take advantage of people of color (Du Bois, 1940).

Since wealth is passed from generation to generation, Blacks in the United States never had the economic advantages that White Americans had. As a result, extreme socioeconomic inequities between White and Black Americans persist (Figure 2). Black wealth in the United States only increased from 0.5% to 1% between 1865 and 1990 (Adelman & Herbes-Sommers, 2003).

Wealth by Race and Ethnicity, 2007-13

Median net worth of households, in 2013 dollars



Note: Blacks and whites include only non-Hispanics.
Hispanics are of any race.
Source: Pew Research Center tabulations of Survey of Consumer Finances public-use data

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Figure 2. Wealth by race and ethnicity.

Race and Racism-Black Health

Black people in the United States face racial discrimination throughout their lives, even when they have achieved middle class or higher status. This constant exposure to social stressors has been theorized to increase health inequities in Black Americans by altering biological development and thus affecting genetics (Geronimus, Hicken, Keene, & Bound, 2006; Kuzawa & Sweet, 2009; Sellers et al., 2009; Williams, Mohammed, Leavell, & Collins, 2010; Williams, Neighbors, & Jackson, 2003; Williams & Sternthal, 2010). Black men may be predisposed to prostate cancer due to the constant psychological stressors from racism, which disrupts the immune system from chronic increased exposure to catecholamines (Ellison et al., 2001; Kennedy, 2009). Racial bias whether perceived or real, affects patient health in addition to satisfaction with healthcare and use of healthcare services (Hausmann et al., 2011).

Current health inequities among Blacks are the result of hundreds of years of racial, social, and economic discrimination along with immoral and inhumane medical discrimination and experimentation. As the oldest, and most oppressed non-White racial group in the United States, Black Americans have never recovered from over 200 years of slavery and over 100 years of government sanctioned segregation and discrimination (Byrd, 2000). The institution of slavery flourished between the years of 1619 until 1862, and it allowed unspeakable conditions and violence towards Blacks (Bennett, 1993). Important discoveries in the field of medicine were often achieved at the expense of Black lives. The surgical technique developed to treat vesicovaginal fistulas was perfected by experimenting on Black female slaves who were not anesthetized (Washington, 2006).

The emancipation of Black slaves in 1863 did not reduce the brutality directed towards them. Segregation and discrimination imposed by the Jim Crow Laws severely restricted every aspect of life for Blacks (Bennett, 1993). Labeling Blacks as less than human was used to justify this mistreatment (Byrd, 2000). To get proper medical treatment; Black Americans began to establish their own hospitals in the 1900s. By 1919, there were 118 Black hospitals in the United States (Gamble, 1995).

The Tuskegee Study of Untreated Syphilis in the Negro Male that began in 1932 and did not end until the 1970s was an observational study of the effects of untreated syphilis (e.g., cardiac and neurological sequelae). It was unconscionable, that this study conducted by the U.S. Public Health Service, continued to go on despite discovery of penicillin as an effective treatment, a national promotion to eradicate syphilis and the Nuremberg trials (Byrd & Clayton, 2002). The Tuskegee investigators effectively prevented local physicians, the Army (for those drafted), and the Veterans Administration (VA) from treating these men. During the 1970s, it was also discovered that some physicians forced Black patients with Medicaid to give their permission for sterilization in exchange for medical care during their pregnancies (Byrd & Clayton, 2002).

Another medical injustice was the development of the immortal HeLa cell line from samples taken from Henrietta Lacks' cervix during her treatment for cervical cancer at Johns Hopkins Hospital (Skloot, 2010). Her cells were cultured and sold without her permission, which improved scientific knowledge of cancer and viruses and contributed to the development of the polio vaccine (Washington, 2006). She died at age 31, and neither she nor her family were compensated (Washington, 2006). Rather, they were blamed for being promiscuous (Jones, 1993; Skloot, 2010). In 2013, her genome was

posted online by researchers at the European Molecular Biology Laboratory (Coghlan, 2013; National Institutes of Health, 2015). This caused increased distress among her family members as this information was now public. The EMBL researchers removed the data and apologized to the Lacks family. However, her family wanted her cells to continue to be used for research. After meeting with representatives from the National Institute of Health, her family agreed to allow access to scientists by formal application and acknowledgement of Mrs. Lacks and her family (National Institutes of Health, 2015).

Race and Racism-The Power of Language

I once saw a video where an elderly Black man stated that when he was a child, he did not mind being called a “nigger,” because he knew that he was not one. However, he was extremely offended if someone called him Black because he knew that his skin color was not black. To him, his skin was brown. He was probably offended because anything having to do with blackness was considered bad. This is a testimony to the complexities of race and racial identity and the power of language. Simply stating the words black, blackness, or darkness invokes thoughts of evil and dirtiness, while whiteness is associated with goodness, cleanliness, and purity (Eze, 1997). The media reinforces these myths and stereotypes, and they are examples of symbolic violence:

Media is an important source of information for introducing, replicating, and reinforcing a society’s dominant ideologies, and as cultural studies theorists point out, these ideologies are often invisible to the media consumer. They often simply confirm what the consumer already “knows” to be true. (Holtzman & Sharpe, 2014, p. 35)

“African American” and “Black” are commonly used terms to describe Americans of African ancestry. They are often used interchangeably with African-American being the more formal of the two (Simms, 2018). The term African-American was a term coined in the 1980s to give Black people a sense of cultural pride and identity, but not every Black person living in this country is African American and not every Black person embraces her/his African cultural identity. American born Blacks often do not consider Blacks from other countries to be African American and vice versa. Historically, numerous terms have been used to refer to Black people, many in a derogatory manner to confer inferiority. Some Black Americans self-identify as Black, many would rather be called African Americans, others want to be called Americans, while others have no preference. Many have very strong convictions about which term should be used. The word “minority” is also used to describe people of color. To people of color, it can be considered offensive, and seen as a subtle way of communicating that a person is somehow “less than” and conveys an inferior status. Merriam-Webster’s Dictionary (2015) defined minority as “a number or amount that is less than half of a total;” “a part of a population differing from others in some characteristics and often subjected to differential treatment;” or “a member of a minority group.” Language can be used as a form of oppression. According to Agar (1996), meaning depends on contexts of the person and “travels well beyond the dictionary, meaning that tells you who you are, whom you’re dealing with, the kind of situation you’re in, how life works and what’s important in it” (p. 16). This word (minority) will not be used in writing to describe any group of people in this study unless it is in a direct quote. Additionally, when referring to the race of an individual, the words Black and White will be capitalized.

Race and Racism-The Power of a Social Construct

Race is an arbitrary classification of groups of people who share common descent based upon perceived innate physical similarities. It is a social construction. This means race is whatever we as a society says it is. Who determines your racial identity? Is it the individual, the government or society? If you self-identify as Hispanic/Latino as your ethnic group and the only options for race were White, Black, American Indian, Alaska Native, Asian, or Pacific Islander, which would you choose? Census and research questionnaires are examples of having someone else determine your identity. For example, I was fortunate to have found the census records of my parents and grandparents while performing an ancestry search. My grandfather was from Italy and his family owned a hotel in the Virgin Islands. My grandmother worked as a maid in the hotel. The two fell in love and had 12 children. The reason I mentioned this is that his race was documented as White on the census when he was a single man living alone but somehow changed to Mulatto when he was living with my very dark grandmother and their children. I never had the opportunity to meet my grandmother because she died in her 50s of heart disease. While my grandfather lived with us and died at 85 years of age. They were both born in the 1880s so as you can imagine, my grandmother had a much harder early life than my grandfather. Did this affect her longevity? My mother is 92 and we have no heart disease in our family.

Although race is a social construct, just being perceived as White affords an individual better health and educational status, even when that individual self-identifies as non-White (Jones, n.d.; Jones et al., 2008). Another example of race as being a socially constructed was the designation of Japanese as honorary whites in the 1960s by the South

African government to facilitate trade relations (Osada, 2002). Perhaps, a more relevant example of race being a social construct occurred in the U.S. during the early 20th century. Jewish people and other immigrants arriving to the United States from Greece, Ireland, Italy, and Poland were not regarded as being White (Dyer, 1997; Ignatiev, 2009). In modern times, however, Americans from these ethnic groups are now considered (or allowed to be) White.

Scientific Racism

There is evidence that discrimination based upon skin color did not exist prior to the Middle Ages (Fredrickson, 2002). Race is a sociopolitical construct. Creating a hierarchy of races protected the position of the White European male to enslave and control inferior races to save them from a barbaric life (Eze, 1997). Condemnation of Jewish people during the 13th and 14th centuries was probably the first documentation of racism. However, Blacks were also targeted. Many renowned philosophers, dating back to antiquity, believed that Blacks were inferior and unintelligent (Aristotle, trans. 1995; Kuehn, 2006; Smith, 2016). The various sciences were evolving at that time, and religion began to have less influence over people's lives. Early anthropologists viewed Africans as incapable of rational thought. Kant believed that the "white brunette" was the original race, and was superior to all other races and from which all other races "degenerated" from. However, much of Kant's knowledge of other races was obtained from reading books written by travelers, such as Captain James Cook's 1773 *Voyages* (Eze, 1997). In *Observations on the feeling of the beautiful and sublime* (1799/2004) Kant stated,

The Negroes of Africa have by nature no feeling that rises above the trifling. Mr. Hume challenges anyone to cite a single example in which a Negro has shown

talents, and asserts that among the hundreds of thousands of blacks who are transported elsewhere from their countries, although many of them have been set free, still not a single one was ever found who presented anything great in art or science or any other praise-worthy quality, even though among the whites some continually rise aloft from the lowest rabble, and through superior gifts earn respect in the world (p.110).

Historically indigenous Africans were among the first scientists and mathematicians. However, very little credit is given to them regarding their contribution to knowledge of the various sciences. The Lebombo Bone, which is a baboon leg bone that contains multiple notches, is one of the oldest mathematical artifacts. It is approximately 37,000 years old and was found in the southern portion of Africa (Bangura & Bangura, 2011).

The mistrust of scientific medicine among African Americans did not begin with Tuskegee Experiment. Throughout history, science has been utilized to assert superiority or inferiority based upon race. This was the beginning of systemic or institutional racism. The traditional hierarchy of the races developed in the 1800s (Jackson & Weidman, 2006). The popular belief at the time was there were five races. They were Caucasian, Mongolian, Malay, American, and Negro. Dr. Samuel George Morton believed that skull size and intelligence were linked (Jackson & Weidman, 2006). This was later used to classify Blacks as subhuman in an attempt to justify slavery. He began to measure skulls and he concluded that Caucasian skull was the largest and the Negro skull was the smallest (Jackson & Weidman, 2006), and was later used to classify Blacks as subhuman in an attempt to justify slavery.

Historically, the oppressive nature of slavery and its associated racism dictated that an individual was classified as Black if he or she had any Black ancestry, the so-called one-drop rule. However, Black people living in America come from a variety of countries, and possess different cultures, ethnicities, experiences, and socioeconomic backgrounds. In addition, Blacks in the United States do not have a homogenous ancestry due to the mixed-race children who were often the product of White plantation owners or overseers, and female slaves.

Some researchers believe that race is a biological phenomenon. However, the evidence does not support this theory (Braun, 2002; Fine, Ibrahim, & Thomas, 2005). According to Braun (2002), “there is more genetic variation within than between different racial and population groups” (p. 163). In recent years, it has been common to consider race a matter of how an individual self-identifies. Nevertheless, “Black” people living in America come from a variety of countries, and possess different cultures, ethnicities, experiences, and socioeconomic backgrounds. In this study, I used “Black” to describe any person of sub-Saharan African descent, and I used the term “White” to describe any person of European origin.

Prostate Cancer and Black American Men

Health inequities are very complex because social, institutional, political, environmental, and individual factors affect them (U.S. Department of Health & Human Services Healthy People 2020, 2014). According to the Centers for Disease Control and Prevention (2014), health behaviors, genes, and biology are only responsible for 25% of one’s health status. Other major influences on health include social environment and social discrimination, such as neighborhoods, schools; social characteristics such as race,

culture, socioeconomic status, gender, disability, sexual orientation; the physical environment, which includes pollution and violence; and healthcare access which includes insurance status.

Cultural norms and values of patients may conflict with those of the healthcare system and with those of the treating provider. Since, patients make treatment decisions based upon their cultural norms, healthcare providers must be aware that Black men tend to mistrust the healthcare system, and they may perceive racial bias in healthcare. As a result, decision-making can be adversely affected (Katz, 2003; Ngo-Metzger et al., 2006). This mistrust may contribute to healthcare inequities, which are the result of historical and present day systemic discrimination and disenfranchisement based on characteristics such as race, ethnicity, religion, socioeconomic status, mental and physical disabilities, sexual orientation, gender, gender identity, or geographic location (U.S. Department of Health and Human Services Office of Minority Health).

Fortunately, the 5-year survival rate for early prostate cancer is 98%, and 80% of cases are diagnosed at an early stage. The type of treatment chosen (surgery, radiation, active surveillance, watchful waiting, or cryosurgery) does not affect mortality rate (American Cancer Society, 2019b; Cancer Stat Facts: Prostate Cancer, n.d.). However, each treatment type has specific side effects that men will have to live with for the rest of their lives (Hamdy et al., 2016; U.S. Preventive Services Task Force, 2008). Thus, choosing a treatment that reflects one's values and preferences through shared decision-making is of utmost importance.

Researchers have found an increase in racial inequities in healthcare when there are multiple therapeutic options requiring complex patient treatment decision-making, as

is the case with prostate cancer treatment (Atkins, Kilbourne, & Lipson, 2014). This may be another factor that has affected prostate cancer outcomes among Black men. There are many unanswered questions regarding the inequities in prostate cancer epidemiology, screening, treatment, and outcomes among Black men (Odedina et al., 2004). Further exploration of the influence of sociocultural factors is needed. While it is important to follow guidelines, it is well known that Black Americans are underrepresented in clinical research (Rogers et al., 2018; Stallings et al., 2000; Woods, Montgomery, & Herring, 2004). Additionally, current guidelines may not be completely applicable to this population. As a result, screening and treatment guidelines may further increase inequities in a population that already has the highest prostate cancer risk and the worst outcomes.

Although age, race, genetics, and family history cannot be changed, there are other factors that can be targeted to reduce health inequities in Black men (Crawford et al., 2003). For example, the influence of socioeconomic status on prostate cancer outcomes must not be overlooked. It has been well documented that an overwhelming number of Black men in the United States live in poverty (DeNavas-Walt, Proctor, & Smith, 2013; U.S. Census Bureau, 2015). Individuals living in poverty have less access to healthcare, and the experience of poverty in childhood negatively affects health as an adult, as does lack of health insurance (Kim & Richardson, 2012; Luo & Waite, 2005). There are many non-biological factors such as culture and poverty, which increase the risk of prostate cancer.

Factors Affecting Prostate Cancer Treatment Decision-Making

Decision-Making Preferences

The emotional connections between patients and providers have decreased as innovations in medical care have increased (Barry & Edgman-Levitan, 2012). Patients are often excluded or are unable to fully understand treatment options presented to them. However, in recent years there has been a shift from paternalistic decision-making to shared decision-making overall in medicine (Roeland, et al., 2014). Requirements for shared decision-making include the following:

One or more clinicians share with the patient information about relevant testing or treatment options, including the severity and probability of potential harms and benefits and alternatives of these options given the specific nature of the patient's situation; The patient explores and shares with the clinician(s) his or her preferences regarding these harms, benefits, and potential outcomes; and Through an interactive process of reflection and discussion, the clinician(s) and patient reach a mutual decision about the subsequent treatment or testing plan. (Alston & Elwyn, 2014, p. 3)

Shared decision-making can be active where patients make the final treatment decision, passive where the provider makes the decision, or shared in which the provider and the patient make a collaborative treatment decision. Shared decision-making regarding one's treatment is necessary for patient-centered care, and it is the *dialogue* that yields necessary information that patients need to make informed decisions about their medical treatment (Epstein & Street, 2007; Fraenkel & McGraw, 2007). It comprises a significant portion of the informed consent process, it promotes patient autonomy, allows patients to

have more control over their care, and it is a vital part of patient centered care (Institute of Medicine, 2003; Entwistle, 2004; Godolphin, 2009).

Shared treatment decision-making requires the patient (and perhaps the family or significant others) to participate, especially when the treatment decisions are based upon patient values, as is the case with prostate cancer. It is no surprise that lack of prostate cancer shared decision-making has been found to increase decisional regret in men diagnosed with prostate cancer, while decreased patient knowledge about prostate cancer is known to be associated with increased decisional conflict (Kaplan et al., 2014). In a study conducted by Sidana et al. (2012), men who felt they were given enough time to make a decision believed that they had participated in shared decision-making.

Studies have also found that most men, including Black men, wanted to be involved in their treatment decisions (Feldman-Stewart et al., 2011). However, men may refrain from participating in treatment decision-making because they do not want to appear as disrespectful (Mullins, Montgomery, & Tunis, 2010; O'Rourke, 2007). Additionally, shared decision-making can be problematic for Blacks because studies have found that physicians may view Blacks as noncompliant with treatment, and less knowledgeable regardless of socioeconomic status (Dovidio, Penner, Albrecht, Norton, Gaertner, & Shelton, 2008). Additionally, when Black patients perceive racial bias or cultural insensitivity, it can lead to less rapport and uncertainty and may prevent them from fully participating (Green et al., 2007; Koerber, Gajendra, Fulford, BeGole, & Evans, 2004; Penner et al., 2010; Siminoff et al., 2006).

While making decisions about one's health can result in apprehension, insomnia, and other negative reactions (O'Rourke, 2007), shared decision-making can improve

health outcomes and aid in the reduction of health inequities (Godolphin, 2009). Palmer, Tooze, Turner, Xu, and Avis (2012) explored how Black men diagnosed with prostate cancer participate in their treatment decision-making and how it influenced their QOL. They recruited 181 Black men diagnosed with prostate cancer from the North Carolina Central Cancer Registry, and the participants completed a cross-sectional survey that asked about their chosen cancer treatment. They found that most preferred active or collaborative decision-making. They also found that the men who preferred a passive role had fewer urinary symptoms. These men also tended to prefer less invasive treatment, were older, and had less education. These findings may indicate that preferred treatment roles, age, and educational levels affect QOL. However, the researcher did not explore the cultural reason for these influences (Palmer et al., 2012). It is also possible that these men believed these types of decisions should be left up to the treating provider. If pressured to actively participate, and their decision resulted in poor outcomes, they could perceive that they made the wrong choice. An interesting study by Wagner, Drake, Elder, and Hebert (2011) explored social and clinical factors affecting prostate cancer treatment decisions. They found that Black men who chose surgery tended to be make their own decisions and did not take the advice of the treating provider. They acknowledged the paucity of research examining racial differences in prostate cancer treatment decision-making and recommended more research on social and personal aspects of decision-making among Black men.

While it is important to determine the treatment preferences of Black prostate cancer patients to prevent poor QOL treatment regret (Palmer et al., 2012), studies have found that providers often do not consider their patients' preferences when determining

prostate cancer treatment (Scherr et al., 2017). Study results here also suggested an independent decision-making influence on predicting surgery, especially among black men. It is important that interventions focus on improving the dissemination of information to men and their social support system about decision-making prior to the medical encounter and encouraging participation in shared decision-making prior to the final decision. These variations in shared decision-making, prostate cancer QOL, and symptom bother after making treatment decision indicates a need for more studies in this area.

The process of treatment decision-making is very complex, and cultural, societal, and structural factors influence it (Penson, 2012). In the case of Black men, cultural factors include their societal and socioeconomic status, education, psyche, masculinity, family, friends, church, other social connections, personal beliefs, values, and experiences, including experiences with healthcare, which have all been shaped by slavery and racism. Societal factors include historical and institutional factors, such as racism and social policies, while structural factors include access to healthcare and the healthcare system.

Cultural beliefs and values play an important role in cancer outcomes because they affect how individuals view health, and how they interact with the healthcare system (Hughes-Halbert et al., 2007). Morris et al., (2015) found that younger Black men experience more treatment decisional regret than older Black men, and older Black men have less treatment regret than older White men. Cultural beliefs also affect patient-provider communication and satisfaction with care (Epstein & Street, 2007). Lack of provider cultural humility (ongoing self-reflection regarding privilege, power dynamics,

and patterns of discrimination) along with the failure to understand patient learning needs and preferences also has a negative effect on shared decision-making. Black American men experience not only inequities in the incidence of prostate cancer, but also encounter inequities in treatment.

For example, Moses, Paciorek, Penson, Carroll, and Master (2010) found that Black men with low risk prostate cancer received more hormonal therapy and less surgery than White men with similar low risk prostate cancer. The rationale was unclear, as hormone therapy is not indicated in low risk prostate cancer due to the low risk of progression, while the side effects of hormonal treatment can be very distressing. Of the 3841 participants enrolled in the study, 304 were Black. The researchers recommended that providers who treat Black patients and other underrepresented groups should be encouraged through education to avoid use of hormonal therapy in patients with low-risk disease. They did not make any recommendations to explore cultural or treatment preferences among Black participants.

Distress after a diagnosis of prostate cancer is common and some studies have found that Black men have higher levels of stress and anxiety when diagnosed with prostate cancer (Campbell et al., 2004; Imm et al., 2017; Orom, Nelson, Underwood, Homish & Kapoor, 2015). However, other studies found that Black men diagnosed with prostate cancer have similar levels of distress as White men, but they report less depression. The researchers pointed out that the self-reporting of depressive symptoms may not be accurate because mental illness is often seen as a stigma among Black people. As a result, qualitative research may open discourse and prove helpful in uncovering

whether these findings are due to stigma or to the unique coping styles of Black people (Nelson, Balk, & Roth, 2010).

Mistrust and Perceived Racism

An increasing number of people receive their news from social media or internet. Unfortunately, the stereotype of Black people, especially Black men, as hoodlums or gangsters is pervasive in the American media (Wallack, 2003). Healthcare providers are not immune to this subtle/unconscious onslaught of negativity and this reality can adversely affect the patient-provider relationship (Institute of Medicine, 2003; Woods et al., 2004).

Racism is a major contributing factor to health inequities (Dailey, 2008; The Institute of Medicine, 2003 Nelson, 2002). While this racism is not overt, it is still harmful. Even when adjustments for socioeconomic status, education, and access to care are made, racially and ethnically diverse patients often receive lower-quality healthcare (Gross, Smith, Wolf, & Andersen, 2008). This is also the case in prostate cancer treatment. Kim et al. (2014) conducted a retrospective chart review to explore why patients choose their specific prostate cancer treatment. The racial make-up was 72 White, 65 Black, and 53 Latino. They found that Black men chose radiation more than White or Hispanic men, and Black and Latino men preferred cryosurgery (freezing). The researchers concluded that race was one of the many factors that influenced their decisions, as Black men did not want to undergo treatments that were too invasive. While there was racial diversity in the sample, this was a small study.

Socio-cultural factors affect patient-provider communication among men diagnosed with prostate cancer, which in turn influence treatment decision-making (Song

et al., 2014). Ravenell, Whitaker, and Johnson (2008) found the major obstacles that prevented Blacks in the United States from seeking healthcare were lack of health awareness, fear, medical mistrust, fatalism, and cultural and linguistic differences (Somayaji & Cloyes, 2015). A descriptive, cross sectional qualitative study using focus groups grounded theory and thematic analysis explored how men made their prostate cancer treatment decision (Berry et al., 2003). There were six Black participants in this study (one Asian and 37 White). While most of the participants researched their diagnosis before speaking to either the urologist, other physicians, friends, family, other men with prostate cancer, looking at written material, or the internet to help make their decision, only the Black participants (and the Asian participant) reported that they did not read any written literature. Additionally, only 10 of the participants discussed this outside information with their treating provider. When the researchers asked the participants of color why they did not read any written materials, these men explained that they felt an urgency to treat to prevent cancer progression. As a result, they accepted the first recommendation so that they could begin treatment in an expeditious manner (Berry et al., 2003). This study indicated that men may make their prostate cancer treatment decisions based upon misinformation, fear, or uncertainty (Berry et al., 2003).

Numerous studies have shown that Blacks are less trusting of the healthcare system than Whites, and they have a higher incidence of unsatisfactory healthcare experiences (Benkert et al., 2006 ; Bustillo et al., 2017; Kennedy et al., 2007; Kinlock et al., 2016; Casagrande, Gary, LaVeist, Gaskin, & Cooper, 2007; Do et al., 2010; Halbert et al., 2009; Hammond, 2010). In a study that examined treatment-based beliefs and coping among men diagnosed with prostate cancer, Black men felt that the care that

White men received was superior to the care they received (DiIorio et al., 2011). Bustillo et al. (2017) found that men who lacked trust in the healthcare system tend to have decreased QOL (Bustillo et al., 2017). An interesting finding was that cancer fatalism was not related to QOL, and the level of fatalism among Black men was equal to that of the Latino and White men. They also found that mistrust was higher in Black men than White men, but about equal to that of Latino men. Racial bias, whether perceived or real, affects patient health, satisfaction with healthcare and use of healthcare services (Hausmann et al., 2011). Xu et al. (2012) found that black men reported less trust in physicians and the healthcare system. However, most viewed watchful waiting as an unacceptable treatment (Xu et al., 2012). In an observational study that explored cultural and socioeconomic aspects of mistrust among 71 Black and 125 White men who were recently diagnosed with prostate cancer, it was found that Black men and men with less education had more mistrust. However, this study did not explore how mistrust affects treatment decision-making.

Religion

Many Black men use prayer to cope with their prostate cancer diagnoses (Jones, et al., 2007). Having higher levels of spirituality or religion in life generally improves QOL in prostate cancer survivors (Krupski et al., 2005), and many studies have found that Black men tend to turn to religion more often than White men when faced with a diagnosis of prostate cancer (Jones et al., 2006; Hughes-Halbert et al., 2007; Krupski et al., 2005, 2006; McFall et al, 2014; Nelson et al., 2010; Odedina et al., 2011; Song et al., 2014). Most studies have found that Black men who have faith in God are more likely to be active participants in their prostate cancer treatment (Maliski, Connor, Williams, &

Litwin, 2010). However, Bowie et al. (2017) found that religious Black men viewed the diagnosis of prostate cancer as punishment or a test, and these men consulted fewer sources of information such as friends, family, or counselors about prostate cancer, from fewer sources than White men with religious beliefs. They also did not believe that they made the made their treatment decisions themselves, and they did not cope as well. They did, however, believe that praying would help to cure their cancer. Studies have also found that Men with prostate cancer who are more optimistic tend to have fewer problems with prostate cancer treatment decision-making (Orom et al., 2009).

Socioeconomic Factors

Race, level of education, income, access to care, and geographic residence all have a tremendous influence on prostate cancer outcomes (Major et al., 2012). Socioeconomic status and access to health insurance affect decision-making in prostate cancer (Dall 'Era, Hosang, Konety, Cowan &, Carroll, 2009; Kane et al., 2003; Rayford, 2006). Kane et al. (2003) found that highly educated men over 75 regardless of race received more definitive treatment and less hormonal therapy for prostate cancer than those with lower incomes. The researchers theorized that this relationship between treatment selection and education is consistent with studies that show that socioeconomic status and education are closely related. Only 9.5% of the men in this study of 3484 men were Black. Level of education also affects health literacy, and low levels of health literacy complicate treatment decision-making. In a study comprised mostly of Black men, Wang et al. (2013) found that only 5% of the participants understood the purpose of the prostate, and 32% or less knew the meaning of incontinence, urinary function, or bowel habits. Steenland et al. (2011) found that prostate cancer treatment varied by race

and geographic status, and that misinformation about prostate cancer diagnosis and treatment is common among Black men (Steenland et al., 2011).

Rural residence also affects treatment choice since many of the people who live in rural areas tend to be poor and have lower educational attainment (Steenland et al., 2011). One study explored the difference in prostate cancer treatment choice by race and geographical area. There were 516 participants (45% Black, 55% White). Investigators found that Black men and men who lived in rural areas who were diagnosed with prostate cancer received less surgery unless they had higher incomes (Steenland et al., 2011). Both groups also had problems communicating with physicians and this often led to lack of treatment particularly among Black men (Steenland et al., 2011).

In a study of 994 participants (583 Black, 411 White) that looked at financial difficulties due to race in cancer survivors, more Black cancer survivors had high levels of debt due to their cancer diagnosis, and they reported not being able to follow-up with their provider for financial reasons (Hastert et al., 2018). However, the focus was not on prostate cancer. It was one of many types of cancers in the study. A prospective study that did focus on prostate cancer, the cost of treatment, recovery time, and effect on daily life were found to be significant factors that influenced the treatment decisions of Black men (Gordon, Basak, Carpenter, Godley, & Chen, 2019). There were 1170 participants in this study, and 304 were Black. Cure was important to both groups (Gordon et al., 2019), and race was not a factor in the type of treatment the men received. This study did not explore cultural factors that may have led to these differences.

Communication and Health Literacy

Americans of all races with fewer than 9 years of education have higher mortality rates from cancer, and lower educational attainment can be linked to poverty. Researchers have also linked education level to prostate cancer (Albano et al., 2007). Black men who achieved less than 12 years of education had twice the risk of developing prostate cancer than those with more education (Albano et al., 2007). This may be another factor in prostate cancer inequities since many Black men live in poverty (Schwartz et al., 2009).

The treatment decision-making process can be more difficult for Black men who have less education and these men may participate less often in the prostate cancer treatment decision-making process (Song et al., 2014). In a study designed to evaluate whether exposure to a CD-ROM shared decision-making program would increase health literacy in 50 Veterans (50% Black, 43.3% White, and 6.7% Asian) with newly diagnosed prostate cancer. They found that most participants chose hormonal treatment, followed by surgery, then radiation after viewing the program. Additionally, many of the participants still had low health literacy scores after viewing the program. Their findings indicate that patients with low health literacy have more trouble understanding the complex treatments associated with prostate cancer. While there were an adequate number of Black participants, the researchers did not indicate whether there were racial differences in the health literacy scores.

Black men have more difficulty with patient-provider communication and less satisfaction with prostate cancer treatment decision-making than men from other ethnicities (Maliski et al., 2004; Orom et al., 2009). The many treatment options for prostate cancer, including prostatectomy, radiation, cryosurgery, or active surveillance

are often confusing. This finding may present additional barriers for Black men due to their overall lower levels of health literacy (Daum et al., 2017; Krupski et al., 2005).

Owens et al. (2019) examined how emotions, beliefs, and past experiences influenced the prostate cancer decision-making process. It was a qualitative study that included 17 Black and 13 White participants. They found that all of the men were surprised by their diagnosis of cancer, especially those aged 65 and over. However, none of the men expressed any decisional regret, regardless of whether or not they had side effects. Finally, having a good rapport and patient-provider communication were the most helpful factors in making their treatment decision-making and satisfaction with treatment (Owens et al., 2019).

There has been much research on the use of decision aids to assist men on choosing their prostate cancer treatments. Decision-aids are computer or web-based treatment decision-making tools that that men diagnosed with prostate cancer can use to assist with their treatment decisions consider clinical and personal factors (Berry et al., 2010). Studies found that decision aids are useful tools in providing patient education, but they do not always result in increased prostate cancer decision-making. (Bosco, Halpenny, & Berry, 2012; Diefenbach et al., 2012; Ellison et al., 2008; Fowler et al., 2012). Unfortunately, most of these studies had few Black participants. Two studies that focused on decision-aids for prostate cancer treatment decision-making in Black men, found that these aids can be useful as a guide to help Black men discuss their prostate cancer treatment options with their treating provider (Ellison et al., 2008; Owens, Friedman, Brandt, Bernhardt, & Hebert 2015). However, a major disadvantage of

decisional aids is that they may not be as useful to men with less education and lower literacy (Kim, 2001; Owens et al., 2019; Rodriguez et al., 2013).

The Influence of Family, Friends and Partners

The influence of the significant others in men diagnosed with prostate cancer has been equivocal. Davison, Oliffe, Pickles, and Mroz, 2009; Srirangam et al. (2003) found that partners of men diagnosed with prostate cancer did not influence their final treatment decision. However, other studies found that partners influenced the treatment decision-making process (Berry, 2003; Chapple et al., 2002; Denberg et al., 2006; Hall et al., 2003; Zeliadt et al., 2010), or they were influenced by men who had been treated for prostate cancer (Denberg et al., 2006; Zeliadt et al., 2010). Additionally, researchers in a qualitative study in which Black men comprised the majority of the participants, found that although men said they made the best choice for “me,” men who chose watchful waiting were persuaded to undergo more definitive treatment by their family and/or providers and they were afraid of cancer progression (Xu et al., 2012). In this study, the men who chose surgery and radiation believed that these treatments offered a cure and were not aware that their risk of death was not higher than active surveillance. The influence of family, friends, and partners is an important factor in prostate cancer treatment decision-making among Black men with prostate cancer. Studies have found that Black men often have more social support than White men, and they seek advice from family and friends more often than White men (Nelson et al., 2010; Wagner et al., 2011).

Provider Recommendations and Urgency to Treat

It is well documented that the patient-provider interaction in medical treatment decision-making is not always a culturally sensitive process (Charles, Gafni, Whelan, & O'Brien, 2006). While providers now encourage shared treatment decision-making, tradition and culture also influence this dilemma. Furthermore, this movement towards shared treatment decision-making may not be readily accepted by all cultural groups (Brannigan, 2012). Some studies have found that Blacks are more likely than Whites to defer medical treatment decision-making to their physicians (Levinson, Kao, Kuby, & Thisted, 2005). Some studies found that Black men tend to have their treatment chosen for them by the treating provider (Do et al., 2010) as do White men (Berry et al., 2003; Davison & Breckon, 2012; Gorin, Soloway, Eldefrawy, & Soloway, 2011; Hall et al., 2003; Sidana et al., 2012). In a study of 231 men (50.6% Black) which looked at factors affecting treatment, Denmark-Wahnefried et al. (1998) found that most men with prostate cancer regardless of race accepted their providers' recommendations for treatment. They also found that watchful waiting was offered more frequently to men who had more education, and hormone therapy was offered to more White men with advanced disease than to Black men with advanced disease. Most of the men (90%) were satisfied with their care, but men who received hormones were less satisfied than those who underwent surgery or radiation (Denmark-Wahnefried et al., 1998). This may be related to the often-distressing symptoms of hormonal treatment.

Xu et al. (2015) conducted a cross sectional study to evaluate racial differences in prostate cancer treatment decision-making and found treatment choices were similar between the two groups. However, as cancer risk increased, both Black and White

patients were more likely to choose to undergo surgery and less likely to receive radiation. Black men tended to continue to want watchful waiting/active surveillance even when their cancer progressed, while White men chose other treatment options. Like previous studies, both groups accepted the providers' recommendations, but in this study, they accepted the providers' treatment recommendations over their personal preferences (Xu et al., 2015).

A qualitative study by Volk et al. (2014) explored men's views on choosing active surveillance. Men who chose active surveillance wanted to "buy time" to avoid treatment side effects and not rush into making a poor decision. They also understood that their cancer was low-risk and "trusted" that their providers would monitor their progress over time. The goal of the men who chose surgery or radiation was to cure or eliminate the cancer. These men did not elaborate on their views of active surveillance. There were 30 participants in this study. The researchers indicated that 28 were White, but there was no information on the race of the other two participants. A qualitative study conducted by O'Rourke (1999) found that the strongest factor in making a treatment decision occurred when the urology provider and the primary care provider agreed on the treatment option. There were 18 participants in the study (28% Black and 72% White).

Kazer et al. (2011) conducted a qualitative study to examine how single men make their treatment decisions and where they obtained information when deciding upon treatment. There were 17 patients (17% Black, 82% White) in the study. Some of the themes that emerged were "going it alone," and "shock" at the diagnosis and variety treatments. These men received most of their information about prostate cancer from written literature, the internet, family, and friends. However, they expressed trust in the

treating provider and accepted their treatment recommendations. Scherr et al. (2017) conducted a quantitative study that explored treatment decision-making, patient preferences, and urology provider recommendations. It was a multi-center study involving four VA medical centers in different cities. The researchers indicated that 74% of the participants were White. It was interesting that there was no mention of the race or ethnicity of the other participants. Like other studies on prostate cancer treatment decision-making, the participants accepted the recommendations of the provider, and the provider decided upon treatment based upon clinical information and not patient preferences (Scherr et al., 2017).

As previously mentioned, most men diagnosed with prostate cancer make their treatment decisions based upon the specialty of their urology providers, and these men do not discuss treatment options with their primary care providers. Gorin et al. (2011) explored the reasons men chose watchful waiting and found that they wanted to avoid erectile dysfunction and incontinence. The researchers did not mention the racial make-up of the participants. Hall et al. (2003) conducted a descriptive study to explore why 315 men chose prostatectomy and brachytherapy (radiation). As with the previous study, the men wanted to avoid side effects but were more concerned about a cure, and they accepted the recommendations of the urology providers. They received most of their information from the urologists, the internet, and medical oncologists. Less frequent sources of information included magazines/print media, radiation oncologist, family/neighbors, other patients, or their spouses. None of the men received any information from nurses, television, or radio. They chose treatments based upon what they thought were the best curative options, and those that would result in the least

amount of side effects. Most of the participants indicated that bowel and bladder problems were the most concerning of the side effects. The researchers said there were no racial differences in the findings. However, the researchers did not document the racial demographics (Hall et al., 2003), making appraisal by readers difficult.

Sidana et al. (2012) looked at prostate cancer treatment decision-making in 488 men under 50. Married men chose the definitive treatment of surgery and radiation more often than unmarried men. Single men had more problems making treatment decisions, which the researcher attributed to the lack of social support. White men received information from urology provider more than non-White men. Men that chose watchful waiting had more provider consultations than those who chose surgery and men with high incomes, and those who were more educated sought the advice of three or more providers. Unfortunately, the researchers did not indicate the race of the “non-White” participants. This is unusual, given the fact that the researchers were at The Johns Hopkins Hospital located in the predominately Black city of Baltimore, Maryland. Orom, Homish, Homish, and Underwood (2014) explored what factors influenced patients to choose active surveillance with 120 participants, 10 Black, 2 Asian, and 107 White. Patients with more education did not accept provider recommendations. More of them sought and received a second opinion. Over 42% of the participants reported an unsatisfactory patient-provider relationship primarily due to feeling coerced into accepting treatment or poor bedside manner. Other reasons for dissatisfaction with the patient-provider relationship concerned the patients’ health status, sexual orientation, race, income, or age.

Loss of Control/Masculinity

A diagnosis of prostate cancer often results in uncertainty and anxiety (Mullins et al., 2010; O'Rourke, 2007). In a qualitative study of 20 couples, (one Black, 20 White), Maliski, Heilemann, and McCorkle (2002) found that fear, anxiety, and uncertainty adversely affected prostate cancer treatment decision-making as men reported feelings of loss of control over their lives. One they realized prostate cancer was a "good cancer," they were able to focus on the "best" treatment and the "best" surgeon (Maliski et al., 2002). Patients who have difficulties with psychosocial adjustment, and those who prefer passive roles, may also have more problems with decision-making. Some studies have found that Black men prefer to cope with the diagnosis of prostate cancer on their own. This may be the result of not having a partner or their traditional views on masculinity, such as self-reliance, control of emotions, and dominance that is displayed as not needing help (Campbell et al., 2004; Dimah & Dimah, 2010; Imm et al., 2017). This may put them at risk for having higher levels of distress (Campbell et al., 2004).

In a qualitative study that utilized focus groups to explore the experiences of 34 Black men diagnosed with prostate cancer, Imm et al. (2017) found that returning to normal was a primary goal. This was one of a few recent studies that explored the prostate cancer experience from a Black man's perspective. Whether they make decisions on their own or involve family, prostate cancer treatment decision-making is often a very difficult task. Consequently, effective health professionals provide adequate and accurate medical information and psychosocial intervention to help patients in the decision-making process.

Men may choose complementary and alternative medicine in an attempt to regain control of their lives after a diagnosis of prostate cancer avoids side effects from surgery or radiation. In a qualitative study that utilized focus groups and content analysis, Boon, Brown, Gavin, and Westlake (2003) found that some men chose complementary and alternative medicine as a way to regain control or because of negative experiences with conventional medical practitioners. While there were Black participants in the study, the researchers conducted it in the United Kingdom, and the men were African or Afro-Caribbean. Porter and Diefenbach (2009) conducted a quantitative study to see why men used complementary and alternative medicine to treat prostate cancer. They found that they used it for wellness and to relieve anxiety. Prayer was most often used, and this was followed by counseling and the intake of vitamins. In this study, 7.7% of the participants were Black. Some men also chose prostatectomy as a way of regaining their perceived loss of control caused by their prostate cancer diagnosis (Ramsey et al., 2010).

Associated with masculinity are loss of control, uncertainty, and anxiety (Berry et al., 2003; Denberg et al., 2006; Gwede et al. (2005). Additionally, patients faced with a diagnosis of prostate cancer are faced with apprehension, insomnia, uncertainty, and anxiety before and even after being treated (Holmboe, & Concato, 2000; O'Rourke, 2007). Despite this uncertainty, patients are expected to rationally participate in decision-making when faced with prostate cancer. Studies have shown that Black men with prostate cancer experience more problems with treatment decision-making, worse QOL, higher and more persistent levels of anxiety, and more treatment regret than White men (Hu et al., 2008; Krupski et al., 2005; Lubeck et al., 2001; Mahal et al., 2015; Penedo, Dahn, Shen, Schneiderman, & Antoni, 2006; Purnell et al., 2011; Steenland et al., 2011;

Zeliadt et al., 2006). In a qualitative study that explored prostate cancer treatment decision-making when choosing watchful waiting (active surveillance) with a sample comprised mostly of Black men, researchers found that most men wanted to undergo aggressive treatment despite having a low risk form of prostate cancer. This may be due to their increased apprehension about having their cancer relapse in the future (Krupski et al., 2005).

A recent study found that among men diagnosed with prostate cancer, more Black men believed that all cases of prostate cancer must be treated. This belief decreased in both Black and White men who had more education and were aware of the controversies surrounding prostate cancer screening and treatment (Orom et al., 2014). Side effects of treatment and potential for cure are also important factors that men consider when making prostate cancer treatment decisions (Jani & Hellman, 2008). The treatment for prostate cancer often results in conditions such as erectile dysfunction and bladder and bowel incontinence, which adversely affect QOL (Hall et al., 2003). Even watchful waiting can have adverse effects, such as anxiety, so effective treatment decision-making is extremely important (Goh et al., 2012). Fear of the side effects of treatment often motivated men who declined treatment for prostate cancer and pursued complementary and alternative medicine (White & Verhoef, 2006). As a result, they declined conventional treatment in an effort to avoid the side effects (White & Verhoef, 2006). They also felt that the physicians trivialized the negative influence of side effects such as incontinence on their QOL (White & Verhoef, 2006). Some men were aware that treatment for prostate cancer does not prolong one's life, and these men were faced with more uncertainty (Chapple, et al., 2002).

Jani and Hellman (2008) found that younger patients chose their treatment based upon cancer cure, but maintaining sexual function was also important to them. Older patients were more concerned with bowel and bladder function (Jani & Hellman, 2008). The researchers did not provide the racial composition of the participants in this study. Hall et al. (2003) found that patients made their treatment decisions based upon the belief that they were choosing the most effective treatment for cure. In another qualitative study in which 14 of the 21 participants were Black, the investigators explored decision-making among men diagnosed with prostate cancer. Men made their decisions based upon the potential for cure and the avoidance of side effects while relying on advice from family and friends (Xu, Dailey, Eggly, Neale, & Schwartz, 2011).

Berry et al. (2003) conducted one of the few qualitative studies completed in the United States that examined personal factors that influenced decision-making. However, only five of the 44 participants were Black. The majority of non-White participants (five Black and one Asian) did not read the written information provided to help with their treatment decision, even though they did not indicate that they had any problems understanding the information on the written consent (Berry et al., 2003). They chose their treatment based upon perceived urgency to treat. Additionally, they made decisions based upon speaking with other men who were diagnosed with prostate cancer, and the content of these conversations were usually not shared with the treating physician (Berry et al., 2003). Denberg et al. (2006) explored how emotions affected treatment decisions in a qualitative study, which included 20 participants (14 White, five Black, and one Latino). They also found that the men made their treatment decisions based upon fear, uncertainty, and urgency to treat, and like the previous qualitative study, these

participants felt a sense of urgency and wanted to be treated right away to avoid spread of cancer. The researchers believed that treating providers should address these emotions during the treatment decision-making process.

Kim et al. (2014) looked at factors that men considered when choosing their prostate cancer treatment. Black men preferred radiation and cryosurgery compared to White men because they felt that these treatments were less invasive. Men who chose surgery thought that it is was the most effective option (Holmboe & Concato, 2000). Another study that looked at the primary factors that men considered when choosing prostate cancer treatment found that men often did not chose watchful waiting because they did not understand its purpose, and they were concerned about cancer progression (Holmboe & Concato, 2000; Zeliadt et al., 2010).

Several studies found that patients often make uninformed choices when choosing prostate cancer treatments based upon side effects because they did not understand the information they received, they received incorrect information, or they did not completely understand the specific side effects are different for each type of treatment, (Bosco et al., 2012; Denberg et al., 2006; O'Rourke, 1999; Zeliadt et al., 2006).

Uncertainty among patients diagnosed with prostate cancer may be due to the variety of treatments that depend upon multiple clinical variables, such as age PSA, Gleason score, and co-morbidities (Rayford, 2006). Although many men feel a sense of urgency to treat, most need more time to consider their treatment options because of the shock and fear they experienced when they learned about their diagnoses (Berry et al., 2003; Chapple et al., 2002; Denberg, et al., 2006; Kazer et al., 2011; Xu et al., 2012; Williams, Stechuchak, Zullig, Provenzale, & Kelley, 2013). It also found that many men

based their prostate cancer treatment decision-making on perceptions rather than facts. Additionally, there is a dearth of qualitative studies that have addressed treatment decision-making by Black men diagnosed with prostate cancer (Berry et al., 2003; Kazer et al., 2011; O'Rourke, 1999; Xu et al., 2011; Xu et al., 2012).

Many of the qualitative studies on prostate cancer treatment decision-making were conducted outside of the United States on primarily White participants (Boon et al., 2003; Chapple et al., 2002; Cohen & Britten, 2003; White & Verhoef, 2003). Researchers in a qualitative study that utilized focus groups found that men diagnosed with prostate cancer have a better understanding treatment options when likely odds of surviving rather than risk of dying are presented (Ilic, Murphy, & Green, 2012). While this was an Australian study and most of the men were highly educated, these researchers also saw a need for exploring this topic with in a more diverse study population. There continues to be very little literature on prostate cancer treatment decision-making process among Black men or about the cultural aspects of decision-making in Black men with prostate cancer (Nelson et al., 2010; Odedina et al., 2011).

Factors that are the result of social injustice, such as racial bias, health literacy, socioeconomic status, and lack of choice are difficult to change, and there has been very little progress made in identifying and modifying factors that influence adverse prostate cancer outcomes among Black men in the United States. While one study did find that Black veterans participation in their prostate cancer treatment was similar to White veterans (Knight et al., 2004), and some studies point to patient treatment preferences as the reason for prostate cancer treatment decisions (Kramer et al., 2005; Sommers et al., 2007, 2008), we must recognize that cultural differences may masquerade as patient

preferences (Armstrong et al., 2006). Failure to understand and address the effect of cultural differences along with societal and institutional influences on prostate cancer inequities is a continuing problem in healthcare. Additionally, cultural competency will be ineffective unless healthcare providers are willing to explore their own biases and to acknowledge the influence of race and racism on healthcare inequities (Geiger, 2001; Suite, La Bril, Primm, & Harrison-Ross, 2007).

Theoretical Framework: Application of Powers and Faden's Theory

I write from a perspective that may differ from many mainstream researchers. My argument follows: It appears that for many citizens, the United States has collectively abandoned its liberal ideology of protecting and safeguarding vulnerable individuals. The nation has done this by dismantling or attempting to reduce social programs, such as Medicaid, Medicare, and Social Security, and it has increasingly embraced a conservative philosophy of neo-liberalism, which focuses on individualism, free market (privatization), and decentralization (Brown, 2003; Eliason, 2015). According to Eliason (2015), Neo-liberalism or “trickle-down economics,”

involves an erosion of government regulation and funding of health and human services and replaces government funding and oversight with a private market economy. This for-profit orientation shifts the system from an emphasis on human rights and quality to one of cost-savings and efficiency and makes all variety of health services into goods for sale. (Eliason, 2015, p. 2)

Neo-liberalism has been blamed for the global economic crisis of 2008, and governments that have adopted the policies of neo-liberalism have been faced with financial upheavals, poor infrastructure, increasing economic inequality, and economic

and social instability (Nonini, 2014). This capitalistic ideology claims to promote fairness by eliminating social welfare programs since these programs are not accessible to everyone (Eliason, 2015). The neoliberal principle of individualization has deemed the *economy* more important than the *community*, and it has adversely affected the U.S. healthcare system (Eliason, 2015). It promotes self- responsibility and unfairly places the blame for physical and mental illnesses on the actions or inactions of an individual while ignoring the larger socio-political context (Brown, 2003; McGregor, 2001). Scarce healthcare studies have been conducted with the social justice framework, possibly because of our movement of responsibility away from communities and more towards the responsibility of the individual for health and illness (Boutain, 2005). This movement away from the community may be a factor in increased health inequities (Boutain, 2005). Lack of media coverage regarding these trends could also be an unexamined factor. Kim, Kumanyika, Shive, Igweatu, and Kim (2010) found that the majority of newspaper articles framed the reasons for health inequities in such a way that it seemed as if the affected individuals were responsible for the causes and solutions. Newspapers occasionally identified societal healthcare and genetic causes, and even less (4%) pinpointed social injustices as a cause (Kim et al., 2010).

The Application of Powers and Faden's Theory of Social Justice

The application of Powers and Faden's (2006) theory of social justice to explore prostate cancer treatment decision-making among Black men will provide a theoretical lens, critical analysis, and fresh perspectives for this longstanding disparity. It will inform the way patient, provider, and system level barriers affect decision-making among Black men are analyzed.

The principle of *well-being* is central to Powers and Faden's (2006) theory. Social determinants affect health and are influenced by laws, institutional policies, socioeconomic status, and social norms (Powers & Faden, 2006). In fact, healthcare associations such as the American Hospital Association and the American Medical Association (AMA) are finally realizing the significant effect of social determinants. Recently made changes allow for all healthcare providers to collect ICD-10-CM codes (Z55-Z65), which capture data on social determinants of health (American Hospital Association, 2018). Additionally, the AMA and United Healthcare have worked together to develop 23 new ICD-10 codes, which address social determinants of health (Robeznieks, 2019).

As noted in Chapter 1, Powers and Faden (2006) asserted that there are six morally necessary dimensions required for well-being to occur. These dimensions are health, personal security, reasoning, respect, attachment, and self-determination. This is a direct contrast to the neo-liberal principle of individualism and provides alternate reasons for poor prostate cancer outcomes among this group of men. *Health* is considered to be normal biological, physical, or mental functioning. *Personal security* requires freedom from physical and biological harm. If an individual continues to experience mistreatment (historical, medical, societal, political, institutional), well-being cannot be achieved (Powers & Faden, 2006). Black on Black crime in poor neighborhoods result in labeling of Black men as dangerous "thugs." The recent increase in the epidemic of shootings of unarmed Black men and boys may be the result of these misconceptions. Insufficient social and educational resources lead to unemployment or underemployment, which in turn leads to poverty and crime.

The third dimension is reasoning, and there are two types to consider. The first is *theoretical reasoning*, which is our intellectual understanding and perception of the world. Lack of knowledge of prostate cancer treatments affects theoretical reasoning. The long history of persistent racism had a negative effect on the mental and physical health of Black men and has affected their worldviews. On the other hand, practical reasoning involves how we choose to live, and is based upon our goals, societal norms, and morals. Respect by others, self-respect, and the ability to appreciate and have empathy for others is essential. For example, Song et al. (2014) found that increased patient-provider communication lead to increased trust and a decrease in perceived racism. In contrast, a lack of cultural humility or compassion by healthcare providers may be perceived as lack of respect for the prostate cancer survivor.

Attachment to others involves familial, intimate, and social relationships. Kazer et al. (2011), found that many men preferred to cope with the diagnosis of prostate cancer on their own, which could be the result of their traditional views on masculinity of not needing help or from lack of a partner (Dimah & Dimah, 2010). Additionally, well-being and justice are adversely affected when an individual is unable to make social connections. The use of religious groups, family, or friends may assist men with their treatment decisions (Maliski et al., 2002). Spouses or partners are also a good source of decision-making support for men regardless of race (Denberg, Beaty, Kim, & Steiner, 2005; Jones et al., 2011; Wallace & Storms, 2007).

Self-determination involves having a reasonable amount of control over our lives and our future. Men diagnosed with prostate cancer tend to feel a loss of control (Maliski et al., 2002). When diagnosed, prostate cancer threatens their personal security, especially

if they feel uncertain about their treatment. This can be further exacerbated when they are unable to fully participate in the treatment decision-making process. Men believe that the treatment of prostate cancer is a threat to their masculinity (Arrington, 2008). Masculinity is important to Black men, so they may become deficient in health due to the psychosocial effect of prostate cancer. This continues especially if there is a lack of attachment. This may occur if the man feels isolated when diagnosed with prostate cancer due to lack of support groups or lack of culturally appropriate information. Additionally, respect suffers when there is racial bias (perceived or real) or when personal beliefs and values conflict with the recommended treatment. Low levels of health literacy in the context of a prostate cancer diagnosis affect reasoning. The inability to participate in the decision-making process can adversely affect self-determination, especially when there is a perception of a lack of Prostate cancer treatment choices. All of these findings reveal an inconsistent and troubling effect on overall well-being for men with prostate cancer, especially Black men with the diagnosis.

Summary

Most men diagnosed with prostate cancer have difficulty in making their treatment decisions due to the complexity and variety of available treatment options and the multiple variables associated with treatment, such as the Gleason score, the prostate specific antigen level, the number of positive cores found on prostate biopsy and the presence or absence of co-morbid conditions (Atkins et al., 2014; Cox & Amling, 2008; Krupski et al., 2005; Showalter et al., 2015). As supported by the literature, many Black men diagnosed with prostate cancer often have additional experiences that affect their treatment decision-making and outcomes. Some of these experiences are mistrust of the

healthcare system, systemic racism, and socio-economic and political disenfranchisement that differ from other ethnic groups (Kennedy et al., 2007; Maliski, Conner, Fink, & Litwin, 2010; Shariff-Marco, Klassen, & Bowie, 2010). Unsatisfactory prostate cancer treatment decision-making ultimately affects overall QOL (Chornokur et al., 2011; Lubeck et al., 2001). As a result, new information and strategies are needed to improve treatment decision-making in Black men diagnosed with prostate cancer.

This literature review for prostate cancer treatment decision-making among Black men found that most studies were quantitative, and there were few Black participants included in datasets, leaving more unanswered than answered questions about treating this disease and alleviating inequities for Black men. Most of the research studies that examined prostate cancer treatment decision-making among Black men were small quantitative studies (Xu et al., 2011). According to Eliason (2015), equal access healthcare systems are not always fair and not always equal. Are overall mortality rates in Blacks improving? Still worse over time? The answers are not clear or sufficiently evidence-based to have confidence in them. There are other important treatment outcomes besides survival. Most of the research on prostate cancer treatment decision-making has focused on decision to screen, QOL, decisional regret and decision-making aids. Additionally, the literature review found few Black participants in all types of prostate cancer studies.

The current literature indicates that prostate cancer treatment decision-making is very complex, and factors that influence treatment decision-making in prostate cancer vary widely. Black men who seemed to have an incomplete understanding tended to choose based on QOL or treatment length, while most patients do not die from low risk

prostate cancer by choosing a treatment based on QOL. However, Black men must be educated that not all prostate cancers are alike. Thus, providers must inform them that if they have high-risk cancer or if their cancer is progressing, choosing a treatment based upon a cure should be considered.

There were few qualitative studies in the literature that focused on the prostate cancer treatment decision-making process and even fewer focused on treatment decision-making among Black men (Berry et al., 2003; Denberg et al., 2006; Kazer et al., 2011; Xu et al., 2011; Xu et al., 2012). Given that qualitative studies seek to bring the perceptions and experiences of participants into the mainstream discourse, this lack of qualitative data suggests a need to include the voices of Black men in the resolution of prostate cancer treatment inequities.

This review of the literature confirms that the experience of Black men with prostate cancer is poorly understood, and there is minimal research on cultural beliefs and values in the prevention and treatment of prostate cancer among Black men (Odedina et al., 2011). Black men hold critical sociocultural factors such as racism (actual or perceived), and mistrust of healthcare providers and of the healthcare system are major barriers to equitable health—this truth cannot be overlooked (Zeliadt et al., 2006). In a recent study of prostate cancer patients by Song et al. (2014), results showed that patient-provider communication increased in prostate cancer patients who trusted their providers, had less perceived racism, were more religious, and had at least a high school education. The findings were attributed to these socio-cultural factors rather than to racial factors. However, race and racism are socio-cultural factors. Social status in the United States and in many parts of the world is determined by the color of your skin.

How these men interact with healthcare providers, family, and friends, and how they obtain their prostate cancer information are only a few factors that influence the treatment decision-making process. It is important to involve more Black men in future studies so that culturally appropriate educational interventions can be developed in an effort to increase their participation in the treatment decision-making process. Importantly, and in support of social justice conversations, more qualitative studies would bring the voices of these men into the dialogue on prostate cancer treatment and decision-making.

As the population in the United States becomes increasingly ethnically and culturally diverse, providers from all backgrounds must be aware of cultural differences among ethnically diverse people so that they may provide effective high-quality healthcare and achieve improved health status for all. The nursing profession, with its emphasis on patient education, disease prevention, health promotion, and holism can be instrumental in assisting prostate cancer patients with their treatment decision-making. According to McGregor (2001), patients must have a basic understanding of prostate cancer and of the anatomy and physiology of the prostate to be able to participate in the decision-making process. I support this contention. I am a nurse researcher and so represent that perspective on prostate cancer research. Nurses can develop innovative strategies to improve educational resources related to prostate cancer and its associated treatment options. Practitioners should present all men diagnosed with prostate cancer with all available options in ways that are easily understood. Additionally, nurses and other providers must remain current in their knowledge of new treatments to help with prostate cancer screening and treatment decisions and emphasize the importance of

increased participation of Black patients in research studies. Our role in research is vital to uncover innovative interventions that can be utilized in our practice to improve the care of those at highest risk.

Health systems cannot be just if the larger social and institutional injustices are not addressed. For social justice to occur, there must be an improvement in well-being for all people (Powers & Faden, 2006). The widespread burden of poverty and its social stigma resulting in lack of respect, disenfranchisement, and abuse that exist among vulnerable populations must be overturned, as well as prevented for future generations. Furthermore, institutional and social policies must be implemented to support well-being (Powers & Faden, 2006). Reducing racial and ethnic inequities in treatment outcomes and satisfaction with care should be a major priority, and institutional, sociopolitical, and cultural factors that may contribute to poor outcomes must be further explored.

The racial gaps in prostate cancer treatment are matters of social justice that must be addressed and never again ignored. Part of social equity involves the voices of the people directly affected, and qualitative studies can do this. There is a dearth of literature on shared treatment decision-making in prostate cancer among Black men. While it is important to follow guidelines, it is well known that Black Americans are underrepresented in clinical research (Ford et al., 2003; Stallings et al., 2000; Woods et al., 2004). Therefore, the current prostate cancer guidelines may not be completely applicable to this population. Caring for patients according to treatment guidelines developed from research studies in which people most affected are not the focus is a major concern. Prostate cancer screening and treatment guidelines may further increase

inequities in a population that already has the highest prostate cancer risk and the worst outcomes (Mahal et al., 2014).

While there is a need for additional research among Black men to achieve reduction in prostate cancer inequities, it is not enough. Barriers to care must be identified and addressed, and clinical interventions that incorporate cultural values are a necessity. In addition, more qualitative research should be conducted to validate existing data and to collect more data on the experiences of Black men diagnosed with prostate cancer, which would be in their own words and from their perspective (Chamie, Williams & Hu, 2015). Adams (2019) states, “My experiences with this specific male-ethnic group has revealed that quantitative interpretations of their perceptions, attitudes and beliefs will never truly provide the full scope of their struggle with this chronic illness” (p. 54).

The use of Powers and Faden’s theory will assist in the development of hypotheses for further research, policies, and practices that may increase the participation of Black men to improve prostate cancer treatment outcomes. Building on the major points of the literature review, the next chapter will describe the research methods I applied in this study.

CHAPTER 3:

METHODS

Introduction

“Every patient has their own story to tell, regardless of their background or our preconceptions” (Annette Fenner Chief Editor Nature Reviews Urology, 2019)

One of the purposes of qualitative research is to give a voice to the voiceless by telling their stories (Patton, 2015). Furthermore, with current emphasis on patient-centered care, the use of qualitative methods can bring human experiences to research and practice (Silverman, 2010). This focused ethnographic study was an exploration of cultural influences on prostate cancer treatment decisions in Black men. It involved the examination of the health beliefs of Black men diagnosed with prostate cancer in the context of cultural, sociopolitical, economic, and environmental factors, along with the interactions between the men and their treating providers. A critical ethnographic perspective informed the study design (Madison, 2012). As Madison (2012) noted, “The critical ethnographer takes us beneath surface appearances, disrupts the status quo, and unsettles both neutrality and taken-for-granted assumptions by bringing to light underlying and obscure operations of power and control.” (p. 5). Although a longer study involving a larger, more diverse sample of Black men and more extensive fieldwork might have generated a more comprehensive critical ethnography, limited time and sample made the study a better fit for a focused ethnography, infused with the critical contexts to the extent possible and opening possibilities for a more detailed critical study in the future.

This study added to the literature by offering a better understanding of how contextual and cultural factors affect the complex process of prostate cancer treatment decision-making so that we may effectively support and address the needs of this population. Learning how Black men make their prostate cancer treatment decisions is important because evidence from the literature suggests that Black men are the group most affected by prostate cancer. Additionally, prostate cancer decision-making among Black men has not been adequately explored, analyzed, and understood thoroughly in the existing literature. This chapter explains the study's qualitative design and rationale for the study. There is also a discussion of the role of the researcher, along with strategies to ensure credibility, transferability, dependability, and confirmability—dimensions of methodological rigor.

Qualitative Research

Qualitative research emerged from the socio-cultural studies conducted by early anthropologists and sociologists. These early researchers examined social and cultural perspectives by immersing themselves in the participants' communities, often situated far from familiar surroundings (Merriam, 2009). The collection of qualitative data by way of direct observation, in-depth interviews, field notes, and examination of written documents (considered archival data) is essential for increasing our understanding of social phenomena. Qualitative research is especially useful for explaining phenomena for which there is little existing research evidence (Creswell, 2018). It can also be used to support or enhance quantitative research, depending on the questions being asked in the study (Miles, Huberman, & Saldaña, 2014). As Patton (2015) observed, "Qualitative research inquires into, documents, and interprets the meaning-making process." (p. 3)

A qualitative design and method were chosen for this study because there are scarce data on how Black men make their prostate cancer treatment decisions. The inductive and descriptive nature of qualitative research offered a better understanding of complex phenomena because of the rich data obtained from the men's interviews. There was a substantial amount of interaction between the researchers and the participants, and the participants' words were used as data, along with research field notes and archival data (Creswell, 2018). Regarding each participant as a unique person, qualitative researchers promote the opportunity to mutually respect differing worldviews and interpretations of reality. Additionally, the research process and outcome occur because of shared experiences and negotiated understanding between the researcher and the participants (Patton, 2015). Developing a trusting relationship with participants was very important in this work, as for all qualitative research (Madison, 2012; Lincoln & Guba, 1985).

Quantitative prostate cancer research has informed us of the poor prostate cancer outcomes, but qualitative research is better suited to describe *why* this is happening in the context of "real life" (Miles et al., 2014). Stated another way, "Doctors who look only at test results and don't also listen to their patients are making judgments with inadequate knowledge, and vice versa" (Patton, 2015, p. 14).

Most prostate cancer studies have been quantitative, and few of these studies included sufficient numbers of Black men for drawing informed inferences. This study provided a better understanding the experience of treatment decision-making among Black men, and of how cultural, historical, systemic, and social factors influence this process.

Research Design: Ethnography, Focused Ethnography and Critical Analysis

Qualitative inquiry is often multi-disciplinary, and there are several specific designs or approaches commonly applied in this type of research, one of which is ethnography. Ethnography represents both a design for qualitative studies and a methodological array of procedures. Evolving from anthropology, basic ethnography provides analysis and description of daily life, beliefs, and behaviors of people within a specific cultural group in a natural setting over a period of time (Creswell, 2018; Merriam, 2009; Savage, 2000). It is naturalistic, which means that it takes place in an uncontrolled (by the researcher) environment, and it is unstructured in the contexts of daily life. Traditional or basic ethnography is generally aimed at vivid descriptions for what is under study, but “It necessarily falls short of the whole” (Fetterman, 2010, p. 11). Issues of power differentials, marginalization, and injustice are not often a part of its focus. In comparison, “critical ethnography has a social justice or advocacy agenda as the guiding purpose” (Madison, 2012, p. 197). Critical ethnographic research is used “in response to current society, in which systems of power, prestige, privilege, and authority serve to marginalize individuals who are from different classes, races, and genders” (Creswell, 2018, p. 92). In the words of Madison (2012), “Critical ethnography becomes the ‘doing’ or the ‘performance’ of critical theory. It is critical theory in action” (p. 16).

The overall purpose of ethnography is to describe and interpret a cultural group or system with an emphasis on human society and culture (Merriam, 2009). Morse (2012) noted that in studies with groups who share a common illness or condition, the participants tend to acquire beliefs and values common to others with the same condition. In such cases, the study may be described as a *focused ethnography*, primarily interested

in a specific group facing a particular challenge. In his final book, Agar (2019) said of ethnography: “Ethnography could even be defined as a means to an end of investigating, learning, and modeling a different perspective. Ethnographers are professional perspective takers.” (p. 100)

Conducting research in a natural setting (as opposed to a contrived or laboratory setting) allowed for a better understanding of contrasting viewpoints of the participants, as well as a view of the patterns of daily activities, communication, and human interaction (Patton, 2015). Ethnography or critical ethnography is an appropriate design choice when the literature is lacking in the description of a cultural group, especially if the group is experiencing injustice from the dominant culture (Creswell, 2018; Madison, 2012).

All ethnographic researchers spend significant time in the field (i.e., natural settings where people live, work, socialize, etc.) utilizing participant observation and interviews to generate data about the specific cultural group (Merriam, 2009). The outcome of their engagement is referred to as thick description—a detailed explanation of intricate, cultural, and social associations of a particular group that allow for broad interpretation of their experiences (Creswell, 2018; Denzin, 2001; Geertz, 1973; Merriam, 2009). With an agenda aimed at disclosing unfair or inequitable situations, thick description commonly evokes strong emotional responses in the readers following it (Denzin, 2001). The intent in this study was to create a genuine and accurate description of a culture as described from the viewpoint of the people participating in the study. The participants’ own words were used as evidence, and the analysis occurred in the context of their cultural lens (Fetterman, 2010).

Critical methodology and perspective open a reflexive discourse of analysis and critique leading to multi-voiced change (Denzin & Lincoln, 2008). Critical ethnography produces actions to promote change when the researcher believes that it is his or her moral duty to intervene to reduce inequities through advocacy (Madison, 2012). Critical ethnographers focus on injustices and violation of human rights in an attempt to eradicate human suffering and promote social justice by exposing underlying power dynamics (Cannella & Lincoln, 2009; Madison, 2012). Oppression due to race, gender, social interaction, and class status are common topics in ethnography (Cannella & Lincoln, 2009). Accurate interpretation and representation are vital in all ethnographies, forcing investigators to consider how our “power, privileges, and biases just as we denounce the power structures that surround our subjects” (Madison, 2012, p. 16). Constant interaction, dialogue, and negotiations between the researcher and the participants influence the final product. I used a descriptive qualitative design for the study, implemented as a focused ethnography, incorporating key contexts in a critical analysis. This preliminary study opened the discourse, awaiting more in-depth and widely sampled studies to extend and activate the interventions needed for change.

Background and Rationale

The imbalance of power created by traditional research may alienate participants from disenfranchised groups, such as Black men who already feel marginalized due to a history of societal and medical mistreatment. Ethnographic researchers work within the social realm of the participants and invite them to help shape how the research will be interpreted. They interpret and record data, engage in difficult discussions, and eventually

disseminate the findings of their research. This is an influential role for researchers because this “interpretation holds a great deal of power” (Madison, 2012, p. 4).

Human injustice along with its causes must be challenged and possible solutions explored when conducting a study like this one (Madison, 2012). An ethnography that incorporates critical contexts past and present examines the values and biases of both the researcher and the participants (Madison, 2012). It explores inequities by focusing on power structures from a historical, cultural, and social perspective. It asks what could be, and fits well with the Powers and Faden (2006) social justice theory, since this theory focuses on health as a requirement for social justice. Current biomedical research is problematic in that it too often disregards Black perspectives and normalizes poor outcomes among Blacks. I chose critically informed ethnography for this study to empower Black men to increase their participation in their prostate cancer treatment decisions.

Role of the Researcher

The researcher is the instrument of observation, analysis, and interpretation in qualitative research (Creswell, 2018; Patton, 2015). In this qualitative study, I was aware of my own social background and my position of power. As a Black American woman, I share the same racial identity as the participants. However, I may have been viewed as an outsider due to my Caribbean roots, my gender, or due to my position as a healthcare provider (advanced practice nurse) and researcher. While working as a urology nurse practitioner, I noticed through my interactions with Black men who were prostate cancer survivors that many were not happy with or did not fully understand their treatment. No one previously asked these men how they made their prostate cancer treatment decisions.

My life experiences as a Black American and my experiences working with Black men who were diagnosed with prostate cancer played an important role in why I chose this research.

Reflections on My Role

My primary interest is reducing racial inequities in health and healthcare. I believe that racial bias and widespread indifference of the dominant culture to social injustices towards people of color increase these inequities. Most of this bias is not intentional. Healthcare providers often do not understand how racial and ethnic populations perceive health and illness. Many are not aware that these biases affect the patient-provider relationship and as a result, the care they provide to these groups (Institute of Medicine, 2003). Those in a position of power or privilege may say or believe that health and social inequities are self-inflicted and have nothing to do with bias (due to race, gender, sexual orientation, age, religion, etc.). Healthcare providers may be susceptible to victim-blaming stereotypes about patients from disfavored groups (e.g., minorities, smokers, obese patients, etc.) who are somehow less deserving. This is what qualitative researchers wanted to avoid. We must dig deep to find the root causes of inequities (e.g., how health and social policies create and perpetrate inequities), and help facilitate change.

This study added to the body of knowledge by focusing on identifying the root causes of prostate cancer inequities among a sample of Black men, from their perspective. Powers and Faden's (2006) social justice theory comprised the theoretical framework chosen to model the work. While prostate cancer is a significant problem, it is also a "symptom" (Madison, 2009, p. 189) of a deeper problem, such as racial bias or

cultural indifference. Madison (2009) asserted “A dangerous ethnography seeks to enter surfaces, but, moreover, enters what is often hidden in plain sight- the convolutions and complications below the surface, the systems that generate and keep surfaces in place” (Madison, 2009, p. 190). My aspiration for this study was that it might be “dangerous” in that sense. I believe it is necessary for me to share my perspective on this work. Since I was the instrument for data generation and interpretation, I reflected on my experiences during the research process.

Sampling and Setting

In my study of prostate cancer treatment decision-making among Black men, I evaluated the experiences of Black men during their prostate cancer treatment decision-making process. This focused ethnography included contextual elements that influence prostate cancer treatment decision-making by Black men treated at various healthcare settings throughout San Diego County in San Diego, California. My hope is that the findings will empower the participants by helping them to understand how historical, organizational, social, and cultural factors influence their prostate cancer treatment decisions.

A combined purposive/snowball sampling technique was chosen for this study. Purposive sampling is a common qualitative sampling strategy in which the researcher chooses participants who have the necessary characteristics and detailed information that relates to the purpose of the study (Merriam, 2009). The snowball technique allows for the participants to refer potentially eligible participants to the study. A purposive sampling strategy allowed the researcher to obtain an in-depth understanding of the

research problem from the participants' perspective, rather than attempting to generalize without their input (Creswell, 2018; Patton, 2015).

There is a potential for bias, but this type of sampling is necessary in order to find participants who are considered to be "information rich" (Merriam, 2009; Patton, 2015). In this study, I recruited the participants primarily via word of mouth and with verbal announcements during church services. Flyers were also posted on local business and distributed at community events. The final sample size was determined as the study progressed. It was based upon the availability of the participants and the time when no new information or constructs came from the interviews.

The sample size for an ethnography is dependent on many factors and is not a fixed outcome of a power analysis or other strategy. In Patton's words, "Sample size depends on what you want to know, the purpose of the inquiry, what's at stake, what will be useful, what will have credibility, and what can be done with the available time and resources" (p. 311). For the institutional review board (IRB)/University of New Mexico (UNM) Human Research Protections Office (HRPO) purposes, I aimed for an approximate sample size of no more than 30 participants. According to Patton (2015), sample size is variable in qualitative studies and may run between 10 and 40 individuals, depending on the previously mentioned conditions. However, it is possible that data saturation may be reached with fewer participants. Saturation occurs when the investigator determines there are no new conceptual categories or information about prostate cancer treatment decision-making emerging from the interviews (Patton, 2015).

Inclusion Criteria

The sample consisted of (a) men who self-identified as African-American or Black, (b) Black men who had been diagnosed with prostate cancer, (c) who had at least one consultation with a urologist related to this diagnosis, and (d) who could speak/understand English. Since 80% of adults in San Diego County have at least a fifth-grade literacy level, it was assumed that the men in this study could read at the fifth-grade level (San Diego Council on Literacy, 2014). Basic reading and writing skills are essential to obtaining proper informed consent. I assumed that the men knew about their prostate cancer diagnoses, had treatment options presented to them, and that they were willing to discuss their beliefs and perceptions regarding their treatment.

This sample will enrich understanding of the experiences of this cultural group (Patton, 2015). As previously stated, the participants were recruited from churches, community centers, cultural groups, local businesses, and word of mouth. Church members referred the majority of the participants. I also invited urology providers to refer appropriate patients to the study from their offices, but no participants were recruited from urology providers.

Study procedures

After obtaining approvals from the University of New Mexico Health Sciences Human Research Protections Office (HRPO), I sent letters explaining the purpose of the study, participant criteria, and study details to the various Black groups, local churches, and community centers in the southeast San Diego. This is where the majority of Black San Diegans reside. I also visited these organizations personally. Once I obtained letters of permission, I posted recruitment announcements in churches and local businesses. My

contact number was included in the letter so that the participants were able to contact me if they had any questions regarding the study. Once potential participants contacted me, I sent more information and arranged specific times to meet with them.

Prior to any interviews, I met individually with each participant and explained the informed consent process to him. I informed each participant of his ability to withdraw from the study at any time, the purpose of the study, the participants' role, the length of time involved, and any potential risks involved in the study. I explained that the interviews would be audiotaped, and that I would be taking notes. The participants were given time to read the consent forms and to ask any questions they had about the form or the study itself. There was no waiting period between informing the prospective participant and obtaining consent unless requested by the participant. To ensure informed consent, the participants were reminded of their right to withdraw from the study at any time, including before, during, and after the one-time qualitative interview.

I developed an interview guide with open-ended questions designed to uncover their beliefs, attitudes, and prostate cancer treatment decision-making behavior and experiences by stimulating patient discussion of events. I asked the participants questions pertaining to their prostate cancer treatment decisions, whether they trusted their treatment provider, and the extent to which they believed the provider influenced their treatment decisions. Descriptive data such as age, level of education, marital status, religious preference, and type of prostate cancer treatment were collected using a demographic questionnaire that I developed (Appendix A). I also developed an interview guide (Appendix B) with open-ended questions as the major source of data to explore the effects of the Black culture on prostate cancer decision-making, their beliefs about

prostate cancer treatment, and their experiences with the healthcare system. Each participant was asked the same questions.

The interviews were located at the participants' site of preference, for their convenience. The settings included public places such as community centers and offices of local churches. To protect privacy, the interviews were conducted in quiet, private areas, which were free from outside observers or listeners. The participants were informed of the study purpose and other factors described above. Interviews were audiotaped and extensive field notes were taken. Field notes are defined as follows:

They [field notes] should be dated and should record basic information such as where the observations [interviews] took place, who was present, what the physical setting was like, what social interactions occurred, and what activities took place. Field notes contain the descriptive information that will permit you to return to an observation [interview] later during analysis, and eventually, permit the reader of the study's findings to experience the activity observed through your report. (Patton, 2015, p. 387)

I kept a reflexive journal, which contained my own frames of reference, voice, and personal interpretation of what was going on in the study, the interviews, any dilemmas that I encountered, and how I resolved them. I also included how I managed my own cultural, linguistic, political, social, and economic contexts as I met and interviewed the men of interest to this study (Patton, 2015). Notes on my thoughts and feelings were also recorded on the interview guide. In the role as researcher-as-instrument, I used the journal to put my voice into perspective, and selectively included anything that directly affected the conversations and data generation with these men.

Data collection ended when there was no new information about prostate cancer treatment decision-making to be uncovered, and no new conceptual categories of information emerging from the interviews. This is called saturation or redundancy (Lincoln & Guba, 1985). There was some indication of saturation and no new participants came forward after the 10 chosen to interview. Given the restrictions of time and recruitment, my Chair and I decided that was adequate.

In a qualitative study, the use of phone calls and intersubjective dialogue varies with individual encounters. Therefore, there is no rigid script that fits each situation. I offered each participant an opportunity after the study to confidentially discuss the findings with me, but a follow-up phone call was not necessary for clarification of topics for the informants.

Data Collection and Data Management

The primary method of data collection consisted of 60 to 90-minute in-depth semi-structured interviews to guide the discussion. Semi-structured interviews are those in which the questions are decided upon prior to the interview. However, the order and the way the questions were posed were not decided ahead of time (Merriam, 2009). The flow and timing rested on the rapport and ease of communication between participant and researcher. Consistent with all qualitative inquiry, the original questions sometimes led to additional clarifying or example-sharing questions, depending on the participant's response and his willingness to expand his feedback to the researcher (Patton, 2015).

Semi-structured interviews were useful because they allowed the researcher to guide the interview so that all pertinent topics were covered for all participants. The interview guide consisted of mostly open-ended questions, designed to stimulate

participant discussion and to uncover their beliefs, attitudes towards prostate cancer treatment decision-making, values, and experiences. The interviews were the major source of data used to explore the experience of prostate cancer decision-making experiences and beliefs about their prostate cancer treatment, complemented by my researcher's notes and reflections.

Interviews began after providing the participants with a brief summary of what to expect. Non-identifying demographic data (age, employment status, highest completed grade level, marital status, religious preference, year of diagnosis, type of treatment [e.g., surgery, radiation, active surveillance]) were collected before proceeding with the semi-structured interview. The interview continued until participants believed they had answered the questions to their satisfaction. All interviews were audiotaped to ensure accuracy of responses. I took extensive field notes. These interview notes allowed for tracking the research activities and allowing reader-outsiders to experience the interactions described in the process (Patton (2015). The notes contained the dates, times, and settings of the interviews, along with any interpersonal interactions that took place (Patton, 2015). Consistent with qualitative inquiry, this strategy provided an audit trail for methodological rigor.

In line with a qualitative design, a reflexive journal was kept to capture my frames of reference, voice, personal interpretation of what was going on in the study and in the interviews, any dilemmas I encountered and how I resolved them, and how I managed my own cultural, linguistic, political, social, and economic contexts (Patton, 2015). The journal helped to put my voice into perspective and provided insight that directly affected the conversations and data generation with the participants.

Effective data management preserved transparency and confidentiality. Each interview had an ID code assigned. A checklist which included each interview date, transcription date and a quality check was developed and maintained as part of the transparent audit trail for this study. A copy of the checklist is provided as an additional document for this dissertation (see Appendix A). A data tracking system was used using items “a” through “g” as follows: (a) each participant had a unique study ID number unrelated to any identifiers. (b) The study ID number was obtained from an online random number generator such as Randomizer.org (<https://www.randomizer.org/>). (c) To ensure confidentiality, transcripts of all interviews and interview notes were labeled with the unique study ID number assigned to each participant. (d) Any personal names that occurred in the interviews was aliased in the transcripts. (e) I transcribed the audiotaped interviews and interview notes. (f) Non-identifying demographic data (age, education, marital status, religion, date of diagnosis, treatment) also used the same anonymous study ID number. (g) Consistent with HRPO policy, all audio recordings were destroyed once the data were transcribed. No protected health information (PHI) was collected or used in any part of the study.

Interview transcripts, informed consent forms, letters, written documentation with identifying information, and any other study documents were backed up, stored, and secured in a locked file cabinet and a password-protected computer in my home. A data tracking system was established. Transcripts of all interviews were labeled with a code assigned to each participant. Audio recording and electronic copies of the transcripts were transferred to my computer (password-protected). Research documents were arranged chronologically and kept in a locked file cabinet until destroyed.

Data Analysis

The interview guide was utilized to document participant responses, using ethnographic methods and the Powers and Faden social justice theory as a guide. The audiotaped interviews were transcribed and checked for accuracy by me. Field notes were recorded into a journal after each interview. They were then transcribed into a Word document, preserved in a password-protected, encrypted computer, and then analyzed. These notes contained questions, problems, and observations. According to Patton, (2015), the field notes “should include the exact language used by participants to communicate the flavor and meaning” (p. 289). The raw field notes, observations, and transcribed interviews made up the collective reality of the participants and their experiences, awaiting my making sense out of them and writing about them (Patton, 2015).

Developing some manageable classification or coding scheme was the first step of analysis. In my initial review of the data, I read the transcriptions while listening to the tapes and reviewing the field notes to sort the data and to look for any errors. I began to develop codes after receiving confirmation from the participants that the transcripts accurately reflect their thoughts. I chose to do this without qualitative software, since the sample was limited, and I could directly engage with the data. Using Word proved to be an adequate capture for the data and my analysis. I was able to either type or write my impressions, early codes, and other notes during the analysis.

Codes are the smallest units of conceptual meaning held in a block of data or a rich sentence. Early codes for all written data were developed after reading and re-

reading the transcripts line-by-line, which helped me to identify categories—common words and key phrases identified in the texts from interviews and notes (Merriam, 2009).

Open coding (making notations on the margins of the interview guide) was initially utilized, and more specific codes were developed during data synthesis and analysis. Consistent with recognized qualitative techniques, each transcript and set of notes were read and coded individually (See appendix B). Then commonly coded arrays of text from across all the interviews and notes were recombined into new texts that were representative of group data across all sources.

A second round of coding of these new texts followed, yielding a set of codes that became a synthesis of all data. I analyzed the codes for how they interrelated to each other. In reflecting on the interrelatedness of the codes, larger units of meaning, commonly known as themes, were generated. These themes were distinct yet informative and comprised the actual findings of the analysis, along with actual quotes from participants which underscored and illustrated the findings, creating a better understanding of how Black men make the prostate cancer treatment decisions, expressed in their own words (Averill, 2012; Patton, 2015).

Determining Data Quality

Lincoln and Guba's (1985) criteria for determining data quality were used in this study. Many qualitative researchers have cited their criteria, and their text *Naturalistic Inquiry* is considered a classic. These criteria were developed to guide qualitative researchers to understand what was being studied and to ensure rigor and trustworthiness, which comprise the truthfulness of the research (Lincoln & Guba, 1985). The four criteria

they established include credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

Credibility is analogous to internal validity. It indicates how closely the research findings match the views of the participants, and it is ensured by validity checks throughout the research process (Lincoln & Guba, 1985). These checks include prolonged engagement to the extent possible; persistent observation, and prolonged contact with participants, as possible; triangulation of methods (using more than one data source, such as interviews, researcher's notes); member checking (in which notes, recorded interviews and early findings can be verified with the participants to ensure accuracy); peer debriefing with either colleagues/peers and or seasoned qualitative researchers; and negative case analysis which involves sampling and examining data until conflicting evidence is found. This allows examination of diverse experiences and referential adequacy (data archiving; Lincoln & Guba, 1985). In most studies, some or all of these activities can be applied.

Transferability can be compared to external validity. However, qualitative researchers do not seek to generalize their findings, but instead to gain insight and find meaning. Transferability evaluates whether the findings can be applied in other settings with similar contexts, and its evaluation resides with the investigators using the data (Lincoln & Guba, 1985). For example, would I obtain similar findings among Black men diagnosed with prostate cancer who were treated in northern California or another state?

Dependability replaces reliability in qualitative research. It involves the development of an audit trail, which is accomplished by precise documentation of study procedures (including reasons for decisions and changes). This allows anyone outside of

the study to follow and see the activities, the challenges, and the resolutions (Lincoln & Guba, 1985). It also provides an opportunity to share the steps taken for research quality when publishing or sharing the study findings.

Confirmability in qualitative studies is used in instead of objectivity (Lincoln & Guba, 1985). This is verification that the data support the findings. Maintaining a transparent audit trail of all research activities, debriefing with my mentors, and reflexive journaling were used to record my actions, thoughts, and feelings about changing conditions in the setting throughout the research process. Application of these criteria strengthened overall trustworthiness (Lincoln & Guba, 1985). Since one of the purposes of this qualitative study was to give Black men a voice to eventually inform change, all participants were given my contact information and invited to call to learn the results of the study. Additionally, a copy of the interview was mailed to each participant with instructions to contact me if the participant believed that the transcript was not an accurate representation of his views. I made a follow-up call to the participants to discuss this and to answer any questions. For this member checking, all 10 of the participants agreed with the transcripts.

Protection of Human Subjects and Ethical Issues

Approval for this study was obtained from the University of New Mexico's IRB (HRPO). This was a low risk study regarding the potential for harm. Benefits and risks were explained to all participants. An important benefit of the study may be that it has the potential to empower Black men to actively participate in their prostate cancer treatment decisions. Risks included the potential for psychological stress, loss of confidentiality, and loss of time. Loss of time was unavoidable since the interviews filled some of that

time. However, participants were asked to allot one to two hours to complete the interview, and they all did so. To decrease risks of harm, I extensively explained the study to the participants prior to the interview. They were also provided with ample time to read the informed consent form and to ask questions about the study. After agreeing to participate, each participant was also given a copy of the informed consent with a detailed explanation of the study and with my contact information.

The consent form contained a clear summary of the study purpose, risks, benefits, voluntary participation confidentiality, and participant rights. These rights included the right to privacy and confidentiality; to receive detailed information on the study; to refuse to participate in the study without negative consequences; to withdraw from the study at any time; to refuse to answer questions if it made them uncomfortable or for any other reason; and to refuse to be audiotaped, (hand written detailed notes would be written to describe the interaction). All of the participants consented to be audiotaped, and none withdrew from the study. Identifying information remains in a locked file cabinet in the researcher's house and will be kept until the dissertation is defended, and all HRPO policies for data destruction will be followed. After this time, the consent forms, transcripts, and logs will be destroyed. I was the only interviewer, and I am the only one who will have access to these documents.

Significance of the Study and Summary

The results of this research will add to the current body of knowledge by extending research on prostate cancer decision-making among Black men, from their perspective. It will especially enrich the understanding researchers and providers have

from the patients' own viewpoint and experience, in their own words, something much needed in the management of this terrible illness.

Patient-provider communication, shared decision-making, and trust affect the quality of care of all patients, not just racial/ethnic minorities or those with low socioeconomic status. However, problems in these areas of patient-centered care disproportionately affect vulnerable populations. Incorporating patients' perspectives on culturally and linguistically appropriate services into current measures of quality will provide important data and create opportunities for providers and health plans to make improvements. (Ngo-Metzger et al., 2006, p. ix)

The approach and rationale for this ethnography, along with procedures for data collection, management, analysis, and methodological rigor were explained here. Steps taken to maintain confidentiality and trustworthiness were also explained. The findings of the study, complete with themes and interpretation, will be presented in Chapter 4. Chapter 5 will include a summary and interpretation of the findings along with implications for nursing and recommendations for future research.

CHAPTER 4:

RESULTS

When a flower does not bloom, you fix the environment in which it grows, not the flower.

(Alexander Den Heijer)

Introduction

Chapter 4 describes the results from this study of the experience of prostate cancer treatment decision-making within the context of culture in a sample of Black American men. The findings are reported and analyzed as distinct, complementary themes, including how these themes answered the research questions.

Sample Demographics and Setting

All of the 10 participants were Black men born in the United States who were living in San Diego County, California. San Diego County has a population of 3.3 million people, and only 5.5 % of the population is Black (U.S. Census, 2010). Most of the participants were born in the Southern or Midwestern states and relocated to California as children or as an outcome of joining the military. Their ages ranged from 50 to 78 years. The majority of participants were married and described themselves as Christians. All had at least a high school diploma, although the majority had at least some college education. Most of them had been living with prostate cancer for at least three years (See 2).

Table 2

Demographic Characteristics

Characteristics	Frequency
<i>Age in Years</i>	
50-60	5
61-70	2
71-80	3
<i>Marital Status</i>	
Married	8
Single/Divorced	2
<i>Level of Education</i>	
High School	3
Some College	4
Bachelor's Degree	1
Post-Graduate Degree	2
<i>Religious Views</i>	
Christian	9
Atheist	1
<i>Type of Treatment</i>	
Active Surveillance	1
Radiation	1
Surgery	3
Active Surveillance	1
Watchful Waiting	1
No Treatment	2
<i>Years Living with Prostate Cancer</i>	
Less than 1 year	2
2-10 years	6
Greater than 10 years	2

Note. $N = 10$

The participants were recruited through flyers, which were distributed to local businesses, and organizations where Black men convene, as well as word of mouth. Some of these places included barbershops, clubs, and churches with predominantly Black

congregations. I tried to get access to the patients of some local Black physicians I was familiar with; however, none of them responded to my request. I thought it would be easy to recruit participants for this study since I was also Black. However, this was not the case. I was told that I would have problems finding Black men who would participate in the study because they associate prostate cancer with its effect on erections (i.e., masculinity, in their view). Prostate cancer is a very sensitive subject for many Black men (Clarke-Tasker & Wade, 2002; Lambert, Fearing, Bell, & Newton, 2002) but the patients in my clinical urology practice had no problems discussing erectile dysfunction. As such, I believed that once the men knew I was a healthcare provider, they would be comfortable speaking to me. Once more, I was wrong. While at a picnic to recruit participants for my study, very few men expressed any interest in the study. I managed to recruit one participant from the picnic, and one from a prostate cancer run/walk. However, it was the local Black churches that became my major source of participants.

The members of Black churches welcomed me with open arms. Just as the Black church often plays a major role in the Black community (Du Bois, 1903/1994), the Black church was central to my study. This opening allowed me to spend more time with the participants in a favorite setting. The only types of church service that I had ever attended were Lutheran, Catholic, Anglican, and non-denominational. I had never been to a traditional Black church (Baptist, Church of Christ, African Methodist Episcopal, etc.). One thing people may not know about traditional Black churches is that the services are very long. They can be so long that comedians often make jokes about them. The services typically last two hours and sometimes even longer.

I remembered one particular church well. I wanted to speak to the pastor after the service. We had spoken briefly before I attended his church, and he had already given me permission to recruit from his congregation. The congregation was predominantly Black and many were veterans, including the pastor. There were over 100 people in the second service. Everyone was well dressed and very friendly. I felt like I was part of the congregation even though it was my first time attending this church. It was a long service, but it was enjoyable because there was a lot of singing, and the sermon was interesting. During the service, visitors were asked to stand and introduce themselves, which I did. Towards the end of the service, when they were making announcements, the pastor said, "I think Ms. Linda also has something to ask of us." I was nervous because I did not expect this. I went to the front of the church and introduced myself, described my study and said that I was looking for participants.

After the service ended, we gathered for snacks. Music filled the air. The younger children were running and laughing while the adults were conversing. People were setting up food and it smelled wonderful. It was more than snacks. There was chicken, potato salad, greens, macaroni and cheese, cakes, and lots of cookies. As we waited for the food, I was discussing my research and future plans with church members. Then three of the men told me that they were interested in participating in the study. I was elated because finding participants had been difficult. I thanked them and then began to feast. After we finished eating, I was told that the pastor wanted to speak to me. He was in his office with many other members of the congregation. He said that he wanted some of my business cards so that he could give them to other people he knew. It was a very successful day for recruiting participants, and I had a wonderful time.

Summary of the Findings in the Context of Themes and Research Questions

Since patients tend to make treatment decisions based upon their accustomed cultural norms, the aim of this ethnographic study was to describe the treatment decision-making experiences of a sample of Black urban men diagnosed with prostate cancer. Following an analysis of all interview data and researcher notes, three major themes emerged from the narratives of the men. The themes were *trust in provider*, *the need for more information*, and *making difficult decisions* (Table 3). These themes were based upon the participants' knowledge and experience and highlighted how institutional racism informed their prostate cancer treatment decision-making. These themes were also linked to the following research questions: Who or what influenced the treatment decisions of Black men? What difficulties, challenges or problems did they experience before, during or after treatment? How did they describe the patient-provider dynamics during their treatment decision-making process? The three research questions were answered by analyzing the participants' responses to the interview questions as well as researcher notes taken after each encounter.

Trust in provider included issues of provider trust and mistrust, patient-provider interpersonal dynamics, and cultural insensitivity of providers. Anxiety and uncertainty, multiple fears, the importance of talking with others, health-seeking behaviors, decision-making challenges, and the need for more time comprised the theme of the need for more information. The theme making difficult decisions, included powerlessness, side-effect challenges, and clinical outcomes for patient.

Table 3

Thematic Matrix

Themes	Codes	Descriptions
Trust in Provider	Trust versus Mistrust Perceptions and Beliefs Patient-Provider Interpersonal Dynamics	<p>Patients' perceived tension and wariness between having faith or doubting that the provider will act in their best interests</p> <p>Patients' perceptions and previous beliefs about prostate cancer; also refers to their underlying religious or spiritual faith or ways of thinking</p> <p>Refers to the provider's cultural sensitivity, cultural humility, and respect for patients' opinions in patient-provider interactions</p>
The Need for more Information	Uncertainty Multiple Fears Importance of Talking with Others Health-Seeking Behaviors Decision-Making Challenges More Time	<p>Anxiety of living with the treatment decision</p> <p>Patients' fear of side effects, recurrence of cancer or death</p> <p>The value and usefulness of reaching out to others and/or being invited to discuss their problems, gain accurate information, and help them decide among options</p> <p>Patients' strategies for finding ways to manage prostate cancer side effects and to monitor for recurrence</p> <p>Patients' difficulties gaining sources of knowledge and understanding of prostate cancer treatments, sources of their information and their perceptions of who made the actual treatment decision</p> <p>Having sufficient intervals between appointments to absorb, reflect, and discuss information about prostate cancer before making a decision.</p>
Making Difficult Decisions	Powerlessness Side-Effect Challenges Satisfactory Clinical outcomes for patients	<p>Patients' perceived loss of control, inability to change cancer progression and loss of predictability about one's life</p> <p>Patients' reality of living with prostate cancer regardless of side effects of treatment even if it changes their lives</p> <p>The well-defined, reliable/consistent assessment indicators that follow treatment; may be symptoms known/described by patients (e.g. QOL after treatments) or objectively determined factors observed and measured by clinicians (e.g. serum levels)</p>

Trust in Provider-Treatment Decision Influences.

Trust in provider is linked to the research question: Who or what influenced the treatment decisions of Black men? Like previous studies, most men accepted their providers' recommendations. However, trust versus mistrust, perceptions and beliefs, and patient-provider interpersonal dynamics encompassed the theme of trust in provider. Studies have shown that Black men tend to have less trust in their treating providers than White men. This mistrust can lead to noncompliance with treatment. Studies have found the men who believed the information from providers to be trustworthy believed they could manage side effects of prostate cancer and were more comfortable with their decisions. While most men stated that they trusted their provider, mistrust was manifested by what some of them said:

"I trust that he knows about surgery but he didn't seem like he was willing to explore anything else. Since it is my body, I didn't trust him to look at all the possible options that would be best for me."

"I find it hard to trust them because I keep getting different answers about the right treatment."

While only two men openly discussed racism, it was an apparent underlying factor. When asked about how to improve the PCa treatment decision-making process some of their responses were as follows:

"Here in San Diego, there aren't too many Black people so they may not be used to dealing with us. You know. They may think that we are all uneducated and can't think for ourselves or that we can't make educated decisions."

“I don’t think that anything can be done to make it an easy decision. I trusted that the doctor was making the best decision. Many Black older people only go to the doctor when they feel sick. This may go back to the old days when most doctors were White and racist and we were not treated well.”

Patient-provider interpersonal dynamics was a crucial factor. Regarding relationships with his providers, one man stated:

“He listened but he didn’t seem to think that the side effects were that big a deal. He said that I could have problems with impotence and leaking, and since I was young and don’t have problems now, it would be easier for me to recover. He couldn’t say with 100% certainty that I would be close to normal. I also go to the bathroom a lot. He says it could be because of the cancer but he is not sure, and he is not sure if it would get better or worse. It seemed like I was bothering him by asking so many questions because he was like, will we will need to schedule another appointment to address all of your questions.”

Another participant summed up his relationship with his provider by saying:

“I don’t think that I have a relationship with any of the doctors that I saw. They wanted to do things their way with surgery or radiation. I wanted to use natural treatments. They also talked about monitoring the cancer. I don’t see why adding vitamins and cannabis to would affect the monitoring of the cancer.”

Ironically, the men who did not trust their treatment providers were happy with their choices. Both deferred definitive treatment and chose to monitor the cancer progression. Another patient was ambivalent about treating his cancer with conventional medical treatments. He appeared to be well informed about various treatments for

prostate cancer, and he was interested using CBD oil and possibly proton therapy, which he found in his own research to have less tissue damage and fewer side effects. He stated he had always eaten healthy foods and he stays in good physical condition. He drastically changed his diet by becoming vegan after learning that it could be a factor in prostate cancer. He reported that he received most of his information from a prostate cancer support group that he attended, books, and the internet. This participant said the support group helped him cope with his diagnosis. He stated that they also discussed innovative treatments for prostate cancer. He said that he also found information on the various treatments by looking at the internet. He gets upset with his physicians because it is difficult to contact his urologist, and his visits tend to be too brief. His facial demeanor appeared to look frustrated when discussing his urologist. To further complicate the interpretation of his responses, his lack of trust in healthcare could be related to the significant racial trauma he experienced as a child from seeing his father killed by the Klu Klux Klan. He stated,

“I don’t know about my father because he died young. I saw him get killed right in front of my eyes by the KKK when I was a child in Alabama. I still remember it like it was yesterday. It was bad for Black people in Birmingham. There is still racism, it’s just a little different.”

Historical or personal racial trauma experienced by Black men was not explored for its role in shaping responses in this study, but his responses suggest the need to do so in future research.

The Need for More Information-Difficulties, Challenges, Problems

The theme, need for more information, includes the concept of “enough time,” and is associated with the research question: What difficulties, challenges, or problems did they experience before, during or after treatment? While the need for trust in provider was a major theme, the need for more information also influenced decision-making. Incomplete information and psychological barriers such as fear, uncertainty, and loss of control affect patients’ decision-making processes. Prior research has found that men wanted more information so they know how to take care of themselves after being treated for prostate cancer (Maliski, Connor, Fink, & Litwin, 2006). It led some men to look for more information, while others accepted the recommendations of the provider. In general, the participants experienced less anxiety and tended to be more active participants in prostate cancer decision-making when they received additional information about prostate cancer treatment.

Most of the participants in this study trusted their provider (Table 3). Half of them believed they needed more information and had no choice in their treatment. Prior beliefs about specific treatments can also affect decision-making. When information about prostate cancer treatments is obtained solely from family and friends, it is not always accurate in the scientific sense. One participant voiced his concerns about radiation as being unacceptable, commenting that,

“I heard people end up feeling worse or dying from the radiation.”

When asked what else he thought I should know about his experiences, another man added:

“Black men need to learn about prostate cancer. We need to educate ourselves. We can’t depend doctors to keep close tabs on our cancer because they have a lot of patients and they don’t think about the patient until we are scheduled to come back. We need to get copies of everything and keep track of our own lab tests and x-rays. That helps a lot when looking things up or if you get second opinions.”

Another participant expressed anger with his lack of knowledge. He stated:

“He answered my questions, but I wish that I had waited to find out more before having surgery. I don’t think I knew enough to make a good decision that is why I am angry.”

Although most of the men expressed that they had enough time to make a decision, time is included as an important element. Not having enough time to process the new information led to anxiety and uncertainty, decisional conflict, and multiple fears among the men who felt rushed. This fear affected health-seeking behavior in this sample. One participant was too overwhelmed to ask questions when he was first diagnosed with prostate cancer. Here was his comment:

“I didn’t ask too many questions I think I was in shock learning about my cancer.”

This participant had good experiences with his healthcare providers up to his diagnosis and he trusted them to make the best decision. However, he was very unhappy with the side effects of incontinence and erectile dysfunction. He thought that he had to act quickly to prevent dying from prostate cancer. He also believed that the urologist should have given him more time and more information to improve his decision-making.

The men who did not trust their providers felt that they needed more time and more information. When asked if he had enough time to make a decision, one said:

“The urologists did not want to give me the time I wanted to make a decision. That’s why I went for second opinions and looked on the internet, then I ended up treating it myself.”

The other participant who also expressed mistrust and feeling rushed increased his time to make his decision on his own by deciding against treatment. Here is what he said when asked if he had enough time to make a decision:

“Yes and no. No because if I had listened to the urologist, I would have rushed to surgery and would probably be wearing diapers now. And yes, because I made took my own time to make the decision.”

This participant also perceived the ability to talk with other survivors as helpful. He stated:

“The prostate cancer support group helped a lot. Speaking to other men who had actually been through the different treatments and hearing their experiences helped a lot. They also had guest speakers who were doctors that were experts in the different treatments.”

Some of the men stated that the providers would not listen to their thoughts on alternative treatments. One participant stated:

“It is a difficult process because they only tell you about their treatments. When I ask about natural treatments, they have no idea, or they don’t want to talk about them.”

One participant said he was unhappy with his decision-making experience not only due to lack of enough information but also the loss of control resulting from his incontinence. He stated that he would not have had surgery if he had understood the life-long complications. He believed that he did not know enough to make a good decision, and wished he had spoken to other men diagnosed with prostate cancer. Another participant believed that his only option to survive prostate cancer was surgery. When I asked about his choice of prostatectomy for his prostate cancer treatment, he stated:

“It was that or die.”

Some of the participants conducted their own research on the recommended treatments by checking the internet to understand the side effects and to look for alternative treatments. One participant who was diagnosed 10 years ago, decided not to follow his provider’s recommendation, and opted instead to use cannabis oil and vitamins. He was college educated, and said he understood the various treatments for prostate cancer. He stated that his QOL was more important to him than simply accepting the recommended treatment. He described that the large studies found that most men with prostate cancer do not die from the disease. His prostate cancer did not progress despite his lack of definitive treatment and believed that his success was proof that conventional medicine causes more problems (and does not want to cure). One reason for his lack of trust in the healthcare system could be related to the fact that his brother died from prostate cancer even though he was treated. In his words:

“Men need to do their own research because I don’t think that conventional medicine is always the best way to go. They don’t always have our best interests at heart. A lot of doctors and the drug industry just want to get paid. Why cure the

cancer if you can't enjoy life because of the bad side effects? I don't think that they care if we are cured or not because the side effects from the treatment keeps us coming back. My brother had surgery and he had horrible problems. Then the cancer came back anyway. He got those hormone shots that made his breasts swell and gave him hot flashes like a woman and he still died even though he did everything the doctor said."

Some participants expressed dissatisfaction with the patient-provider encounters and believed that the providers glossed over the potential side effects or did not adequately address their concerns. One stated:

"I tend to look things up myself because as I have said before, they don't seem to really care about my opinions or me. It is difficult to get to speak to them on the phone. They also want you to make appointments which are difficult to get and when you get there, they seem to be in a rush. I have had better luck with the support group."

While another said:

"He scheduled a follow-up in three weeks. I had a lot of questions and I don't think the appointment time was long enough. I did not have all of the information I felt that I needed to make such a big decision . . . Doing my own research through the internet has helped me the most. The urologists did not want to give me the time I wanted to make a decision. That's why I went for second opinions and looked on the internet, then I ended up treating it myself."

Uneven patient-provider power dynamics were revealed when one of the participants revealed that the provider refused to discuss alternative treatments.

“They wanted to do things their way with surgery or radiation. I wanted to use natural treatments. They also talked about monitoring the cancer. I don’t see why adding vitamins and cannabis would affect the monitoring of the cancer.”

While other expressed decisional regret due to not knowing enough about their decisions:

“He answered my questions, but I wish that I had waited to find out more before having surgery. I don’t think I knew enough to make a good decision that is why I am angry.”

Making Difficult Decisions-Decision-Making Influences

Making difficult decisions is connected to the research question: How did they describe the patient-provider dynamics during their treatment decision-making process? Black men have been found to have more difficulty and less satisfaction with prostate cancer treatment decision-making than men from other ethnicities. Men described feelings of powerlessness once their treatment choice had been made and after they developed side-effects. Although the cancer had been managed, some did not expect to have to live with side effects forever. The following comments illustrate side effect challenges:

“I trusted my doc at first. But now I am not so sure. He should have talked more about these problems that surgery causes.”

“The urologist seemed trustworthy. I’m glad that I am alive, but I didn’t expect to have to live with these side effects for the rest of my life. I am not happy because of my continued side effects.”

The participant who contributed to these comments was diagnosed 6 years ago. He was still seeing the same urologist that diagnosed and treated his prostate cancer at the time of the study. His persistent side effects have made him now question his treatment decision. Most of the participants who stated that they trusted their urologists expressed satisfaction with care, despite having side effects of treatment. Even the two of the participants who did not trust their providers were also satisfied with their care. This was probably because they did not have side effects since they did not receive definitive treatment. In both cases, their cancer also had not progressed. One self-treated with natural therapy (diet, cannabis, etc.), while the other opted for active surveillance (monitoring the cancer with yearly prostate biopsies).

Quality of life was important to the participants. The providers' goals of treatment for some of the men conflicted with those of the patients themselves. The treatment decision that results in the eradication of prostate cancer was a satisfactory outcome for the provider. However, the patients who had different expectations expressed dissatisfaction with treatment decision-making, suggesting that providers need to focus more on side effects and talk about the different treatment options. This was reflected by the following statement:

"They make it sound like you will be back to normal after the surgery."

While another participant stated:

"There are a lot of options with prostate cancer treatment so it can be difficult to choose because of all of the side effects. I am a healthcare provider and it was difficult for me. I think I should have taken more time to look at the different side

effects for surgery and radiation. But the doc made radiation sound so bad, I didn't see it as an option."

He continued to say:

"I feel that the way the side effects were explained to me, it made me think that they would only be temporary. Now I feel that I have little control over this part of my life-the incontinence and erections."

One participant stated that he did not have problems making a decision. He stated:

"It was easy for me. They told me that if I had radiation and it came back they said surgery was not going to help. So, I wanted surgery. I heard from so many from other people about how radiation treatment affects your body."

While the decision was easy for him, he did make his decision based upon misinformation, since both surgery and radiation are equally effective. It should be noted that the providers made the treatment decision for most of the participants.

Many men acknowledged the need for more education from sources other than their providers and this could help them make better decisions.

"Black men need to learn about prostate cancer. We need to educate ourselves. We can't depend [on] doctors to keep close tabs on our cancer."

Men also relied on prayer and their faith in God to help get them through the treatment decision-making process.

"My faith in God has gotten me this far."

When asked how he felt about his prostate cancer diagnosis and treatment, one participant said he was surprised that he was the youngest man in attendance at the prostate cancer class. Black men often develop prostate cancer at a younger age than

White men, and like many Black men, he did not think that he was high risk. He said he was not too worried because he did not have pain. He seemed to associate and attribute pain to the severity of his cancer. He admitted to getting a little emotional, but his attitude was positive when he stated:

“What do we do now?”

He reported that he made the decision and reports the decision-making experience as positive. He seemed to base his decision-making on information he received from friends, fear of the cancer returning and recommendation of the urologist. He also seemed to believe that the seriousness of cancer is associated with increased pain. He stated:

“I really was not that concerned because there was no pain there was no sickness there was nothing no symptoms or nothing to say you got it. It was just like the rise of the blood test. If there was pain that might have made a difference but there was no pain. So, I didn't really know what to think.”

He also spoke about loss of control, which he viewed as a challenge and he believed that his easy-going personality and his faith in God helped him through the process.

The majority of men in this study were satisfied with their PCa treatment decision-making. However, most of the men in this group were middle to upper middle class, well-educated Black men who were able to get second opinions if they disagreed with their providers. Their strong ties to the church or other social groups allowed them to use prayer and community knowledge to facilitate the treatment decision-making process. The men who were not satisfied exhibited mistrust of the healthcare system but managed to regain control by undergoing treatment after conducting their own research and/or by developing an alternative treatment plan.

Most of the men reported that they had good rapport and positive experiences with their urology providers and with their other providers. They also trusted their providers and many of the men stated that they would have gotten a second opinion if they did not trust their providers or if they disagreed with the plan of treatment. Most of the men were college educated, had insurance and a regular source of income. As a result, they had more of a choice in choosing their healthcare provider than Black men with fewer resources. They were in the position to do so, as opposed to Black men with limited sources of income and limited or no insurance.

A previous study found that men who chose surgery reported seeking more guidance from family and friends, and Black men sought advice from family and friends more often than did White men (Xu et al., 2011). In this study, most men discussed their prostate cancer diagnosis with their significant others. However, they typically relied on their provider to guide them in the decision-making process. Some of the difficulties, challenges, or problems they experienced were anxiety and fear related to the diagnosis and treatment, understanding and receiving adequate information from the provider, and coping with side effects of treatment. Table 4 summarizes participants' responses in relation to thematic findings.

Table 4

Synthesis of Interview Questions and Responses

Participant	1001	1086	1017	1027	1013	1012	1081	1099	1098	1066
Provider Trust?	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes/No	No	Yes
Need more Info?	No	No	No	Yes	No	No	Yes	Yes	Yes	Yes
Satisfied?	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	N/A
Side Effects?	Yes	*	No	Yes	Yes	No	*	Yes	*	*
Provider	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes

Decision?											
Discussed with Others?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Difficult Decision?	No	No	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes
Enough Time?	Yes	Yes	Yes	No	Yes	Yes	No	No	Yes/No	Yes	Yes
Had Choice?	Yes	Yes	Yes	No	Yes	Yes	No	**	No	No	No

Note. *Pt did not have definitive treatment ** Participant unsure if he had a choice of treatment options

Methods

In this study, data were collected from semi-structured interviews in order to describe the experience of prostate cancer treatment decision-making among Black men. Lincoln and Guba's (1985) criteria for determining data quality were applied in this study approval obtained by the University of New Mexico Human Research Protections Office, and all appropriate procedures were followed. Key individuals from churches, local businesses, and community organizations in the Black community were contacted. After their approvals were obtained, recruitment flyers were posted. A purposeful sample of men who were diagnosed with prostate cancer was recruited for this study. The interview sites included libraries and offices of churches and/or organizations. I conducted all interviews after obtaining informed consent. The data included audio recordings and field notes in which I recorded my reflections. Data collection and thematic analysis occurred simultaneously. I transcribed the interviews verbatim from the transcripts and cross-checked with the recordings to verify accuracy. Field notes were selectively coded for insights related to the research questions. Codes were assigned to distinct constructs and ideas that were refined during second level coding. Critical reflection was utilized to assign the codes into themes. As themes emerged they were reviewed to ensure

independence. A thematic matrix was used to organize the data, and analysis was ongoing throughout data generation, comparing new data with prior data.

Methodological Rigor was achieved by utilizing Lincoln and Guba's (1985) criteria of credibility, transferability, dependability and confirmability. Credibility was ensured by validity checks, persistent observation and prolonged engagement, member checking, and peer debriefing. Reflexivity and the use of an audit trail were utilized to establish transferability and dependability. Confirmability was also achieved by reflexive journaling and the audit trail as well as frequent debriefing with my mentors. Participant and direct observation included performing participant interviews, and going to the church services, picnics, and social events to mingle with the people attending.

Transferability was achieved by providing thick or vivid description. My descriptions of the details of the participants, the setting, and how data were collected and analyzed will allow other researchers to determine if my findings could be applied to other settings with a similar context. Identifying strategies to improve prostate cancer decision-making among Black men in this sample could possibly be transferable to other groups of Black men such as Black veterans, but additional research is needed to explore this possibility.

Summary

As I was listening to the men, I was surprised to find that the majority trusted their treating providers, and that perceptions of racism did not appear to be a predominant reason for dissatisfaction with prostate cancer treatment decision-making. Most had satisfactory patient-provider communication. The men in this study used spirituality,

faith, and trust to cope with their diagnosis of prostate cancer, and this seemed to have a positive effect on their treatment decision-making satisfaction.

I wondered if the participants would open up and say more had I been a Black man. As a woman and a healthcare provider, I was an outsider to their experience. As a woman, discussing their fears and intimate details of their lives may have raised issues surrounding their perceived masculinity. Some of the men may not have shared as much information because of my position of power as a healthcare provider. I was part of a dominant subculture of healthcare, and to them I represented a group that traditionally has been unable to recognize racial bias in care. While they trusted me enough to participate in the study, they may not have felt that they knew me well enough to have candid discussions about race and racism, unlike the long-term patients in my practice who know me well. As a Black person, some may have considered me an insider, as most Black Americans realize that it can be difficult to escape the day-to-day assaults of racism in all levels of American culture. However, like all other groups, Black Americans are not homogenous and not all believe that their race matters in everyday life (Cheatham et al., 2008).

The findings in this study are specific to prostate cancer decision-making among Black men in one sample who were diagnosed with prostate cancer. As a small qualitative study, findings are not generalizable to Black men outside of San Diego County. In light of these findings, the focus for Chapter 5 will be an analysis of the implications for practice, research, and education of culturally competent care providers. Powers and Faden's (2006) social justice theory will be used to guide the interpretations. Findings will be compared and contrasted with those in the extant literature, especially

concerning the influence of culture. Researcher reflections on the study, its processes, outcomes, and limitations will be included. Study limitations, recommendations, and implications for nursing will also be examined.

CHAPTER 5:

DISCUSSION

It is time to refocus, reinforce, and repeat the message that health inequities exist and that health equity benefits everyone (Kathleen G. Sebelius, Secretary, HHS)

Introduction

It should be no surprise that ineffective prostate cancer treatment decision-making in Black men often results in decisional regret and decreased QOL, especially since making important decisions is stressful even under optimal conditions (Diefenbach, & Mohamed, 2007; Hu, Kwan, Saigal, & Litwin, 2003; O'Rourke, 2006). Since the majority of men with prostate cancer live for extended periods of time with the disease, it is important to make fully informed treatment decisions (Morris et al., 2015). The cultural and historical trauma experienced by Black men complicates the treatment decision-making process. The purpose of this qualitative study was to explore the experience of prostate cancer treatment decision-making among Black men. Chapter 5 includes a discussion and interpretation of the findings of the study, its limitations, implications for nursing, and recommendations for future research.

Effective prostate cancer treatment decision-making in Black men is dependent upon having patient-provider trust (Jones et al., 2006). Several studies have found that Black men had little trust in healthcare providers or the healthcare system (Benkert et al., 2006; Bustillo et al., 2017; Casagrande et al., 2007; Do et al., 2010; Halbert et al., 2009; Hammond, 2010; Kennedy et al., 2007; Kinlock et al., 2016). However, most of the men in this study trusted their treating providers, although one participant developed doubts about his trust when he experienced side effects from the treatments. When seeing a

provider for the first time, uncertain as to potential racial intolerance, many Black patients wonder if they will encounter prejudice or misunderstanding. Black people tend to have more negative experiences with providers, and microaggressions are common. They also have less trust of the healthcare system due to the many documented cases of medical mistreatment, such as the 1932 Tuskegee Syphilis Experiment (Brandon, Isaac, & LaVeist, 2005; Byrd & Clayton, 2002; Centers for Disease Control and Prevention, 2015). For many, it may be difficult for them to trust someone who is part of this same healthcare system regardless of their race. Studies have found that the patient provider relationship is less positive for Black patients (Penner et al., 2010), and a study of unconscious race and social class bias among first year medical students found that most favored White people (Haider et al., 2011).

All of the men in this study believed that trust was important, and all but three of the men in this study trusted their treating provider (one developed mistrust after he developed side effects from treatment). The most important difference between the men who had mistrust and those who trusted their providers was that the men with mistrust did not accept the recommendations of their treating providers. Their decision to forgo definitive treatment went against their providers' recommendations. They believed they needed more information, and that prompted them to obtain more information by doing their own research. It also may have allowed them to feel more in control. In contrast, those who trusted their providers believed they had enough information to make a good decision. While the men with provider trust believed they had enough information to make a decision.

Most of the men did not mention racism overtly, but there were implicit references to racism in relation to personal, historical, and cultural factors. One participant stated, “Since it is my body, I can’t assume that they will act in my best interests.” This is a commentary on his experience with racism. Perspectives of the men’s experiences with racism influenced their treatment decision-making. When observed through a cultural and historical lens, the side effects of prostate cancer treatment are problematic for Black men. It is analogous to the loss of masculinity Black men face with daily microaggressions and is linked to the historical castration and incontinence that often occurred with lynching (Cooley, 2004; McGovern, 1982). When one of the participants described their father being lynched, he was implicitly relating the diagnosis of prostate cancer to racism and the physical manifestations of lynching (see Figure 3). Additionally, negative experiences with healthcare, fear of treatment side effects, and provider mistrust prompted one participant to choose alternative therapy for prostate cancer. This is consistent with previous studies that found that men who declined definitive treatment for prostate cancer and pursued complementary and alternative medicine often had negative healthcare experiences or were motivated by fear of the side effects of treatment (Boon et al., 2003; White & Verhoef, 2006).

From a cultural standpoint, the use of traditional medicine was evident with the exploration of complementary and alternative medicine, which included cannabis oil, vitamins, diet, and even prayer. Scientific medicine is associated with the European dominant culture and considered superior because it is evidence-based. The inequality between complementary and holistic medicine versus scientific medicine becomes racialized when providers refuse to consider alternative treatments as options, and that

potentially aggravates inequality between Black patients and their providers. Nurses are in an excellent position to address complementary and alternative medicine in the management of prostate cancer since their focus is on wellness and the whole person.



Figure 3. Claude Neal was forced to eat his own genitals, shot, and hanged.

Most of the men in this study received definitive medical treatment, which is in contrast to previous studies (Barocas & Penson, 2010; Harlan et al., 2001; Hoffman et al., 2003; Morris et al., 1999; Underwood et al., 2004; Wu et al., 2005). The higher educational attainment level of this sample may explain this. Half of the men had at least some college education, and stated that they understood the information. More educated men often have fewer difficulties with prostate cancer treatment decision-making

(Krupski et al., 2005; Orom et al., 2009), possibly because having more education allows for a better understanding of the complexities of treatment.

Most of the men felt they had received enough information, enough time to make a decision, had a choice of treatment, and were satisfied with their treatment choice. Prior studies found that good patient-provider communication increased trust and decreased perceived racism (Song et al., 2014). Treatment decision-making also improved when the patients felt they had enough time to make a decision (Sidana et al., 2012). Studies have found that spouses or partners are helpful in prostate cancer treatment decision-making process in men of all races (Denberg et al., 2005; Jones et al., 2011; Wallace & Storms, 2007). Community and family are important to Black men, and the literature demonstrates that Black men also tend to be influenced by social support groups and their family and friends when making prostate cancer treatment decisions (Maliski et al., 2002; Nelson et al., 2010; Griffith, Allen, & Gunter, 2011; Rim et al., 2011; Wagner et al., 2011). As a result, having enough time was an important concept to the men in this study. Some of the participants reported feeling rushed or having limited access to their healthcare providers. There was not enough time during the clinical visits for the men to address their fears. Taking time allows the men to discuss their diagnoses with their families, partners, or support groups to help them accept and integrate the illness into their lives. As one participant stated,

“Everything that I went through with all the surgery that I had, I did it because I knew that I could get better by rehab because that's the type of person I am. I'll see what the doctor says and it was almost like a challenge for me to get better.”

In this study, most men discussed their diagnoses with their partners, but it was unclear whether they influenced them. In this study, their friends and support groups seemed to have more of an influence than their partners.

Spirituality also played a major role in this study as it does Black American culture (True et al., 2005), and the men in this study used spirituality and faith to cope with their diagnoses of prostate cancer. For the men in this study, spirituality seemed to have a positive effect on their treatment decision-making satisfaction.

As found in previous studies, the men in this study received most of their information from their treating provider (Hoffman et al., 2018; Zeliadt et al., 2006; Jang et al., 2010; O'Rourke, 1999; Sommers et al., 2008), and they tended to accept the recommendations of their providers. This is consistent with previous studies (Berry et al., 2003; Kazer, et al., 2011; Xu et al., 2011; Levinson et al., 2005; Zeliadt et al., 2006).

Theoretical Application of Powers and Faden's Theory of Social Justice

Morse (2017) stated that "A theoretical framework is a representation of what a researcher thinks is happening in reality... Theory usually consists of interrelated concepts about a particular topic" (p. 72). Morse (2017), Meleis (2018), and others have noted that theories can describe, explain, or predict something of interest to clinicians and/or researchers. The Powers and Fadden (2006) social justice theory was chosen as the framework for this study, serving as a lens for the study of Black men's prostate cancer treatment decision-making experiences. Powers and Fadden designed the theory to ask, "Which inequalities matter most?" (p. 5), along with an analysis of "how inequalities of one kind beget inequalities of another kind" (p. 5).

Powers and Fadden (2006) aimed their theory at shaping justice in public health and health policy, and it has relevance for this study. This theory has not previously been applied in the study of prostate cancer decision-making among Black men. According to Powers and Fadden, there are six dimensions required for well-being. Based on their social justice theory, satisfaction with prostate cancer treatment decision-making can be predicted if the six dimensions of health, personal security, reasoning, respect, attachment, and self-determination were met. Chapter 2 defined and clarified the dimensions. The six dimensions of health will be explored as they relate to the findings to see what Black men need to achieve well-being after being diagnosed with prostate cancer.

The dimension of *health* may be affected by the actual diagnosis, as well as by side effects of prostate cancer treatment. *Personal security* cannot be achieved if there is a constant fear of cancer recurrence. This dimension can include an even broader sense of security in terms of having sufficient resources (health insurance, access, transportation, etc.) to be able to manage their treatment. *Reasoning* is also important because Black men diagnosed with prostate cancer cannot make effective decisions without adequate information and time to process the information, analyze its implications, and understand the outcomes. The theory suggests that if men are aware of side effects, they may have fewer QOL issues if they develop side effects. It may also prevent them from making decisions based on misinformation about treatment. Treating providers can begin by asking men what they already know about prostate cancer and attempt to clarify any misperceptions and build rapport, leading to a more trusting patient-provider relationship.

Providing sufficient information and time is also needed to ensure adequate reasoning. For some patients, this may require two or more visits.

Respect is also a requirement for well-being. Black men may experience a lack of respect whether real or perceived (Cheatham et al., 2008; Doescher et al., 2000; Paez et al., 2009). This may be due to a documented history of racial discrimination and daily microaggressions they may face. These contextual and historical factors can lead to distrust. Providers should be aware of how racial discrimination among Black patients can affect their relationships with healthcare providers and their willingness to accept treatment recommendations. Established patterns of racial discrimination towards Blacks have negatively affected their overall well-being. Alternatively, patient-centered communication is viewed as respectful and non-threatening (Hammond et al., 2009). Hammond et al. (2009) found that physician-centered communication is often perceived as one of bias, power, and control, and it is often utilized more with Black patients, frequently perceived as racist, and creates feelings of powerlessness, especially among Black men.

The fifth dimension in this theory is *attachment*, particularly to people or human-centered resources. Without attachment, Black men diagnosed with prostate cancer may self-isolate due to side effects of treatment such as incontinence. Treating providers who are knowledgeable about the need for attachment by patients are encouraged to recommend resources such as support groups, since some men find them to be helpful (Katz et al., 2002). The final dimension of *self-determination* can be compromised if there is no shared treatment decision-making. This can occur when the goals of treatment differ from those of the patient or if the provider refuses to discuss alternative therapies

medical or complementary therapies. I would suggest that providers should become aware of their specialty biases and offer referrals to other specialists to discuss alternative treatments. Taking this action would allow for increased participation and more informed treatment decision-making so that the patient can choose a treatment with side effects that he is capable of managing (Elstein et al., 2005; Mullins et al., 2010; O'Rourke, 1999, 2007; Scherr et al., 2017; Sommers et al., 2008; Zeliadt et al., 2006).

The physical and psychological side effects of a prostate cancer diagnosis have an overall effect on health and well-being. As a result, most dimensions of this theory should be met for men to have a reasonable QOL while living with prostate cancer. In reality, men may not always be able to meet most of the dimensions at all times. Effective healthcare providers could identify and explore factors that prevent each dimension from being met regardless of whether they are healthcare related (see Figure 4.). In the busy daily work of providing healthcare, this commitment to additional communication, and problem-solving with patients may be shared with other members of the healthcare team (e.g., nurses, psychologists, health educators, etc.), to benefit the men and their families who are affected and improve their health outcomes. This can be accomplished by providing culturally appropriate resources to patients, and by participating in policymaking and developing interventions to assure that well-being can be met.

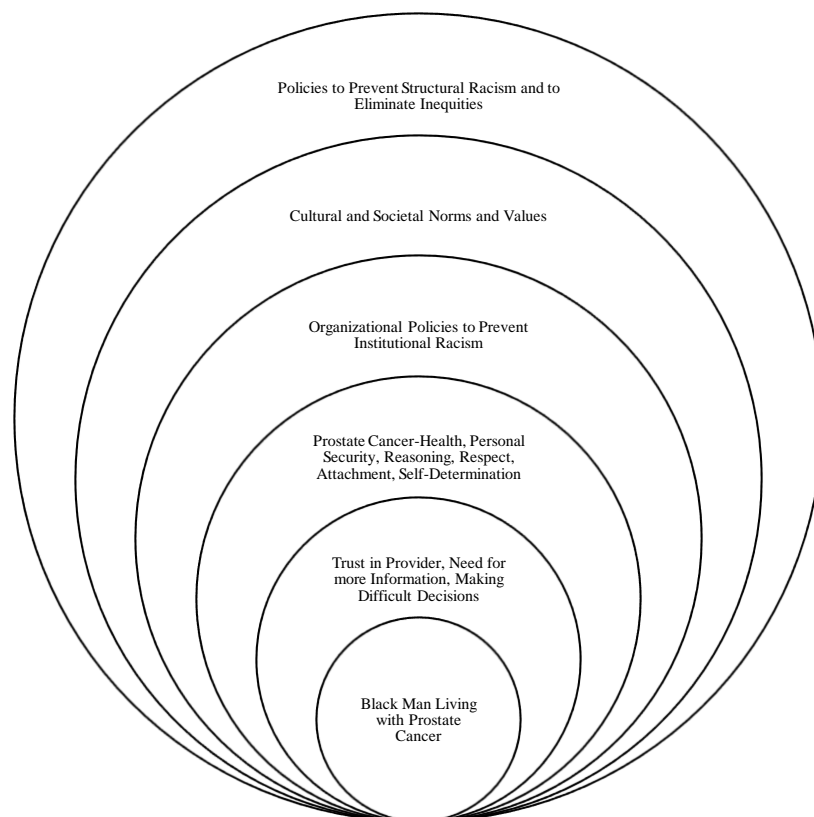


Figure 4. Well-Being in Black men diagnosed with prostate cancer.

Limitations of the Study

Prior to conducting the study, the researcher proposed two possible limitations to the work: limited generalizability of findings and potential researcher bias. In reflecting on the completed study, likely study limitations include: (a) The socioeconomic status and educational level of the participants in this study were not representative of Black men in the United States. Most of the participants had some college education and 30% had at least a bachelor's degree, whereas only 17.9 % of Black American men 25 years of age or older are college graduates (U.S. Department of Commerce, 2010). Also unknown is the influence of urban versus rural dwelling Black men, or factors related to social determinants across the lifespan of the men. The purpose of ethnography is to study a

specific group. Thus, generalizing to the general population of Black men is not feasible, since the study has no comparators for participants in different socioeconomic categories. (b) Possible factors related to my own experiences as a Black person, advanced clinician, and health sciences researcher may have influenced my interpretations in a qualitative study in which the investigator is the instrument and analyst of inquiry. (c) Most of the men did not discuss racism in their healthcare encounters or past experiences. It is also possible they may have assumed that I understood the racial dynamics since I am also Black, or alternatively, they could have been silenced by my position of power as a healthcare provider and researcher. Sampling bias was also a possibility. Lastly, due to time constraints, there was limited time in the field.

Implications for Nursing Practice and Recommendations for Future Research

Health inequities in prostate cancer are inextricably linked to culture and to social injustices among Black men. Understanding how the historical, sociocultural, economic, and psychological aspects of race and racism affect Black men is foundational to addressing and eliminating these ongoing inequities.

In the past, researchers overtly believed Blacks to be mentally and physically inferior to Whites (Tucker, 1994). Current studies have found racial bias persists among healthcare providers and healthcare researchers. Additionally, some may harbor beliefs about genetic inferiority (Tucker, 1994).

The question of genetic differences between races has arisen not out of purely scientific curiosity or the desire to find some important scientific truth or to solve some significant problem but only because of the belief, explicit or unstated, that the answer has political consequences. Rather than an injustice that needs to be

rectified, social and political oppression thus becomes the rational-indeed, the unavoidable-reflection of natural differences. (Tucker, 1994, p. 5.)

Long before Jews, Hungarian, Italians, and Russians were accepted into mainstream American society, they were regarded as being less intelligent than or inferior to White Anglo-Saxon descent. For many years, researchers have explicitly attempted to prove that White men of northern European descent particularly those in higher socioeconomic classes were somehow superior to people of color, the poor, foreigners, and women (Tucker, 1994). At least some aspects of persistent health inequities among Blacks in modern times may be seen as the consequence or modern-day version of these views.

The basic principles of bioethics are autonomy, justice, beneficence, and non-maleficence (Beauchamp & Childress, 2012). Social justice and health equity are corollary ethical injunctions. For example, some key provisions in the American Nurses Association's code of ethics in nursing include the promotion of personal health, safety, and well-being; health as a universal right; obligation to advance health, and human rights; and reduction of health inequities through scholarly inquiry, research, and health policy development (American Nurses Association, 2015). Most healthcare providers uphold the ethical principles of beneficence and non-maleficence. However, the areas of autonomy and justice need improvement in the treatment of Black men diagnosed with prostate cancer and in many other areas where health inequities exist. Fully ethical care and research cannot be achieved without scrupulous respect for autonomy and justice. Nurses and other healthcare providers should consider it the eradication of unjust systems as their ethical responsibility (Grace & Willis, 2012). Racism has caused suffering and

death for people for color for hundreds of years. Therefore, I propose that racism, like pain, can only be felt by those who experience it. The first step in solving any problem is to admit that there is one. Racism is an important factor in health inequities and attempts to deny that perpetuates inequities. As Bill Maher put it, “Denying racism is the new racism” (“Bill Maher: Denying Racism,” 2011, Oct 7).

There is very little research on how Black men diagnosed with prostate cancer make their treatment decisions. Studies examining whether Black men’s cultural views on masculinity, which include putting their families before themselves, contribute to their prostate cancer health inequities are especially needed (Cheatham et al., 2008). Additionally, research studies with larger sample sizes are needed, as the underrepresentation of Black men has been an issue in the studies of prostate cancer. Future studies should be multidisciplinary in nature, according to Chornokur et al. (2011), since many nonmedical factors influence prostate cancer treatment decision-making and its associated treatment inequities.

Black veterans are another underrepresented group in prostate cancer treatment decision-making research, and additional studies are needed (Zeliadt et al., 2012). Approximately 12% of veterans are Black (National Center for Veterans Analysis and Statistics, 2019; Trivedi, Grebla, Wright, & Washington, 2011). Like Black non-veterans, Black veterans have higher rates of prostate cancer than White non-veterans and White veterans. Black veterans also have comparatively higher rates of Agent Orange exposure, and it has been associated with the development of higher risk prostate cancer (Ansbaugh, Shannon, Mori, Farris, & Garzetto, 2013; Chamie et al., 2008; Shah et al., 2009). To increase the presence and influence of the Black veterans’ perspective, more

qualitative studies are also needed to examine whether factors such as culture and health literacy influence treatment decision-making among Black veterans. Including these additional qualitative studies supports the Powers and Faden (2006) advocacy for voice, social justice, and the importance of the six dimensions.

Removal of the financial barriers in equal access healthcare systems such as the VA does not mean that there are no additional barriers to treatment (Saha et al., 2008). Many assume that there are no racial inequities in healthcare at the VA (Reddy et al., 2018). However, personal experience and the findings from previous studies show that this is not the case (Nambudiri et al., 2012; Samuel et al, 2014; Vigil et al., 2015; Vigil et al., 2016). Even so, the VA has been a leader in the fight to eliminate health disparities by developing interventions with the participation of the patient, provider, and healthcare system with a goal of achieving culturally appropriate patient-based care (Atkins et al., 2014). I would argue that the use of the term color-blind is, in itself, problematic because it potentially erases a person's identity. According to Sullivan (2006), it establishes White dominance by disregarding other races and by overlooking the problems of inequality caused by race. Therefore, color-blindness should not be the goal of efforts to improve health equity; rather more direct efforts are needed to reduce race-based inequities.

More studies are needed to explore the decision-making processes of Black veterans diagnosed with prostate cancer, as the review of the literature found scarce studies that focused specifically on decision-making processes among Black veterans. Additionally, the VA recommends that researchers conduct more qualitative studies to elicit, interpret, and understand the Veterans' perspectives and to examine racial inequities in care (Saha et al., 2008).

Research has shown that Black men turn to trusted and respected members of their communities for health information (Musa, Schulz, Harris, Silverman, & Thomas, 2009) and they prefer racially concordant support groups (Maliski et al., 2006). Therefore, it would be beneficial for healthcare system stakeholders to collaborate with trusted Black leaders and Black institutions, like ministers and churches in the communities, respectively, that they service, in an effort to build trust and to encourage more participation of Black men in research (Jiang, Narayan, & Warlick, 2018).

Additionally, partnerships between healthcare systems and with Black communities would allow Black men to participate in the formation of health policies. Informal social networks, such as barbershops, are helpful for generating information for men not as willing to share in church (or who are not churchgoers). This research found that these Black men utilized religion to cope. Previous studies have found that church-based screening interventions have been effective (Drake, Shelton, Gilligan, & Allen, 2010; Holt et al., 2009). As a result, creating church-based prostate cancer support groups would be a positive step in the right direction.

Researcher Reflections

As a Black woman, I can relate to the feelings of mistrust and disrespect that some of my patients experience because I have the shared experience of being part of the non-dominant group. However, I am aware that I have many privileges as a person raised in an upper middle-class family outside of the United States. I did not have to face the daily racism (overt or otherwise) that many of my participants encounter. Additionally, my position as a clinician and scholar gives me a position of “authority,” which I must use carefully and wisely.

I became interested in this topic because many of my Black patients expressed dissatisfaction with their prostate cancer treatment decisions. There are a multitude of studies on a wide variety of prostate cancer issues such as screening, treatment outcomes, and inequities, among others, yet Black men continue to have the highest prostate cancer morbidity and mortality rates. Does being an African American man put a patient at an average risk or at a higher than average risk? If they are at a higher risk, is it from genetic, cultural, or socioeconomic factors? Most participants believed the decision to be their own. When one of the participants said that his decision-making experience was positive and that it was “his” decision, I wrote in my journal: *“Is it really his decision to undergo surgery?”* He seemed to base his decision-making on information he received from friends, fear of the cancer returning, and recommendation of the urologist. Studies have found that treating providers usually recommend the treatment modality related to their specialty. Urologists tend to recommend surgery while radiation oncologists usually recommend radiation. The side effects associated with each type of treatment are different. Would he have chosen to undergo prostatectomy if he had information that incontinence was less likely with radiation? Despite numerous studies, we are still not much closer to answering these questions.

It has been almost 20 years, and goals of the CDC’s Health People campaign, which were “to increase quality and years of healthy life and to eliminate health inequities” have not been met (Centers for Disease Control and Prevention, 2015, 2019). The problem with many of the prostate cancer studies conducted on Black men is that they often failed to consider important factors such as racism, attitudes, and beliefs towards health, illness and death, culture, or past experiences with the healthcare.

Socioeconomic inequality is an increasing problem for all racial and ethnic groups in the United States and is a major contributing factor to the problem of inequities (Neckerman & Torche, 2007). However, when studying Black Americans, the historical issues of race and racial inequality further complicate the issue of socioeconomic inequality.

Race, racism, a unique culture, the long history of medical, sociopolitical, and economic abuse that Black people face result in socioeconomic hardships are tied to inequities in prostate cancer and other health inequities. As we know, prostate cancer and most other cancers and preventable illnesses continue to affect Black people at disproportionate rates (American Cancer Society, 2019a), and Black men continue to be twice as likely to die from low-risk prostate cancer (Mahal et al., 2018). This seems to be expected and accepted by the healthcare community as lower expectations for Black health is “par for the course.” Most physicians and many other healthcare providers have not experienced poverty and have difficulty relating to the growing number of patients who are living in poverty (Howley, 2018). In 2018, fewer than 4% of medical students were Black (Gordon, 2018). The nursing profession is more diverse, with 11.5% of nurses identifying as Black. The movement of hospitals and medical groups away from poor urban areas towards wealthier suburban neighborhoods also contributes to health inequities (Thomas, 2014).

I plan to use my position of power as a clinician and scholar to improve the health outcomes for Black men diagnosed with prostate cancer. As nurses, our goals are patient advocacy and relief of human suffering. We as healthcare professionals are contributing to health inequities and social injustice if we fail to advocate for our patients. Our patients come from a variety of cultures and have different views and perspectives that may be

different but not necessarily wrong. We must take time for self-reflection regarding our biases and self-awareness of other cultures and try to incorporate our patients' different views or lifestyles when we prescribe treatment plans. Even highly educated, insured, White patients feel uncomfortable opposing their physicians' treatment plans because they believe they would be viewed as difficult or that it was socially unacceptable and would result in unsatisfactory patient-provider relationships or less than optimal treatment outcomes (Adams, Elwyn, Legare, & Frosch, 2012; Frosch, May, Rendle, Tieibohl, & Elwyn, 2012). I can only imagine what our less educated, socioeconomically, disenfranchised patients of color feel.

All healthcare providers hold a position of power and privilege regardless of our race. When nurses utilize the medical model of distancing ourselves from patients in an effort to be professional, and use our power to persuade our patients confirm to our beliefs, this may result in lack of trust, which is very important to Black patients. The current trend in patient-centered care is a much-needed movement away from the paternalistic medical model that dominated medicine. It is crucial to have information provided by patients regarding their fears and concerns surrounding treatment so that we know how to approach decision-making discussions.

Social justice research can be utilized to develop innovative strategies to eliminate health inequities. New nursing theory and practices, along with new health and social policies can help to reduce the gaps in healthcare among Black Americans and other racial/ethnic minorities. Further expansion of these models through qualitative research will further theory development, since qualitative inquiry invites multiple voices into the discourse. Health inequities will not be eliminated until researchers advocate for

improving the lives of their patients, and have an increased awareness of the affected populations' points of view (Underwood et al., 2005).

Summary of Dissertation

Feelings of loss of control are common when diagnosed with prostate cancer. Being in control is part of masculine psyche of Black men (Maliski, Rivera, Connor, Lopez, & Litwin, 2008). The diagnosis of prostate cancer provokes feelings of fear, loss of control, or of being attacked. The side effects of prostate cancer may cause feelings of stigma and a potential for humiliation. The diagnosis of prostate cancer is not the only source of powerlessness. It also is evident in patient-provider interactions when the provider is unwilling to discuss alternative treatments. For Black men with prostate cancer, the nature and severity of treatment side effects and perceived inequalities between scientific or biomedical care and holistic care, which includes alternative medicine and traditional or complementary practices, are among many spaces where racism creeps in. Evidence has shown that patient-provider trust enhances decision-making. Lack of provider humility or unwillingness to discuss alternative treatments reported by the men may have left them feeling angry, violated, and powerless which are the same feelings evoked when confronted with racism.

The major critical theme was that prostate cancer treatment decision-making among Black men is influenced by their shared cultural knowledge and experiences of past and present racism in society and in healthcare, requires provider humility and trust in provider, along with and the ability to integrate the diagnosis into their psyche by acceptance and understanding of prostate cancer treatments and its side effects. While studies have documented racism as a factor in poor healthcare outcomes, very few of the

participants directly discussed racism as a factor in prostate cancer treatment decision-making. However, it was mentioned in the context of trusting the provider to make the best decision. The need for trust is important for any patient provider relationship. However, it is especially relevant in Blacks due to the history of social economic and health inequities caused by racism in the United States. Treating providers must be aware of how culturally induced concerns and the historical sociocultural and socioeconomic aspects of race and racism affect the decision-making experiences of Black men diagnosed with prostate cancer.

I was told,

“No Black man is going to talk to you about prostate cancer because he would be admitting that his parts don’t work.”

Fortunately, I was able to gain the trust of some Black men diagnosed with prostate cancer. Thus, the findings in this study may be specific to this group of men who were willing to participate in research in which they shared very personal stories, and are specific to prostate cancer decision-making among Black men diagnosed with prostate cancer. These findings may not be generalizable to Black men outside of San Diego County.

This research demonstrated, trust is essential for patient-provider relationships and cultural humility is an important element of building trust. As such, it would be reasonable to assert that building rapport between researchers and participants is an essential part of increasing research participation by under-represented groups thereby allowing researchers to better appreciate the causes of and hopefully eradicate health inequities (Tervalon & Murray-Garcia, 1998; Yeager & Bauer-Wu, 2013).

Racism is the root cause of racial and ethnic healthcare inequities (Institute of Medicine, 2003). While Powers and Faden's (2006) asserted in their theory that the most important inequities are the ones caused by oppressive systems, their model is focused more on the individual. However, these oppressive systems, which may include healthcare systems, criminal justice systems, educational systems, socioeconomic, and political systems, are maintained by racism and are not controlled by the individual. Well-being may be temporarily achieved, but how long will it last if these oppressive systems remain in place through exploitation, exclusion, indifference, and microaggressions? Since racism is embedded in our society, one cannot separate race from health inequities. Additionally, one cannot separate power and money from racism. Profit and power are the motivating factors for racism and most forms of exploitation. Keeping Blacks powerless enabled this country to amass profit. In modern times, the new plantation owners are the corporations who are exploiting their workers by dismantling unions (loss of power), paying low wages, or by keeping them in for-profit prisons.

Masculinity, independence, and control are important to Black man. Historians have documented continued assaults to their masculinity to exert control through symbolic and physical violence. Calling a Black man "boy" or using stereotypes to classify Black men as lazy, dangerous, or rapists are examples of symbolic violence, which often led to physical violence. There is a "racial contract" where domination and control of Black bodies is considered the norm (Mills, 1997/2014). For Black men, a diagnosis of prostate cancer results in powerlessness, loss of control, and dependence on the healthcare system that threatens their masculinity (symbolic violence). The physical violence is the prostate cancer treatment. The side effects of treatment connect their

history (castration and lynching, which resulted in loss of continence) to present day reality of castration and incontinence due to prostatectomy, radiation and hormonal treatment.

I answered the three research questions by analyzing the participants' responses to the interview questions, along with the researcher's notes. Most of the participants described a trusting relationship with their provider, which suggests at least satisfactory patient-provider dynamics. However, they also described feeling rushed and having difficulty with or not having enough information prior to the decision, which could indicate problems with patient-provider communication. While most of the men did not mention racism, having a higher socioeconomic status gave them more choices that would not have been available if they had fewer resources. Lack of health awareness, health literacy, fear, medical mistrust, fatalism, and cultural and linguistic differences have been found to prevent Blacks from seeking healthcare in general (Bustillo et al., 2017; Powe, 1995; Ravenell et al., 2008; Song et al., 2014). More studies exploring these factors among Black men with prostate cancer are needed to decrease prostate cancer inequities among this group. Without additional research with sufficient Black participants, treatment guidelines cannot be evidence-based. Additionally, understanding the cultural beliefs and values will increase cultural humility among providers. This will allow for a more trusting and respectful patient-provider relationship and follow through with treatment recommendations. According to Cheatham et al. (2008), "Patient perceptions of racism may be difficult to eradicate, but with consistent effort on the part of healthcare providers, trusting relationships that foster health-seeking behavior can be developed" (p. 561).

The process of prostate cancer treatment decision-making is very complex. The participants' accounts of their experiences illustrate how the cultural and historical trauma experienced by Black men complicates this already complex process. Since there is no consensus on treatment, "patients' values, desires, and healthcare beliefs must be included in any treatment decision" (Smith, 2012, p. 169). Plowden, John, Vasquez, & Kimani (2006) found that Black men would participate more if they "trusted and respected community member, a safe and caring environment and a perceived benefit" (p. 147). Utilizing safe spaces such as churches to provide prostate cancer education may be part of the solution.

Most of the men in this study were religious and were active participants in their care. This was similar to the literature which found that Black men who have faith in God are more likely to be active participants in their prostate cancer treatment (Maliski et al., 2010). The QOL among men diagnosed with prostate cancer who also have religious or spiritual beliefs tend to have better than men who do not have these beliefs since they are able to use their religious or spiritual beliefs as a coping mechanism (Jones et al., 2006; Hughes-Halbert et al., 2007; Krupski et al., 2005, 2006; Nelson et al., 2010; Odedina et al., 2011; Song et al., 2014).

Another important issue that was not addressed in this study is that Black men were often not aware that they have a higher risk of developing prostate cancer and other chronic illnesses than Whites (Benz, Espinosa, Welsh, & Fontes, 2011). Screening programs have been successfully implemented in barbershops. However, education about prostate cancer treatment and side effects should be incorporated into these programs. Black men should also be educated about their increased cancer risk and strategies to

decrease their risk of developing cancer. Some of this can be accomplished through community outreach programs at local businesses, churches, and other organizations in the Black community (Cheatham et al., 2008).

Despite the persistence of health and healthcare inequities, the news is not all bad. Black men diagnosed with prostate cancer have been found to demonstrate a greater sense of resiliency than White men (Nelson et al., 2010). Showing them their resiliency is more beneficial than always comparing them to the dominant group, which unintentionally implies that they are not as good. Giving more information on how they have improved, and how overall Black health can be improved with research through trusted institutions can increase their participation in research studies, and give a voice to those who have been silenced for too long. If we do not become vocal advocates for these patients, we perpetuate institutional racism. In the words of Dr. Martin Luther King, Jr: “There comes a time when one must take a position that is neither safe, nor politic, nor popular, but he must take it because conscience tells him it is right.” (King, 1986/2003)

APPENDICES

APPENDIX A:**UNIVERSITY APPROVALS****Data Management Checklist for Protocol, Item 11.0**

ID Code Assigned:

Interview Date:

Transcription Date:

Demographic Questions Answered:

Interview Questions Answered:

Need for Follow-up Call?

Outcome of Follow-up Call, if Needed:

Date of Destruction of Audiotape, Following Transcription:

Researcher's Notes Checked for Additional Relevant Data:

Secure and Appropriate Data Storage for Duration of Analysis (Describe Briefly):

Additional Remarks (optional):

APPENDIX B:

RECRUITMENT LETTER

Recruitment Announcement for Black/African American Men Diagnosed with Prostate Cancer

Your Help is Needed for a Prostate Cancer Treatment Decision-Making Study

My name is Linda Ottley, a Nurse Practitioner specializing in urology. I work full-time at the VA San Diego Healthcare System. I am conducting a prostate cancer study in partial fulfillment of academic requirements for a PhD degree from the University of New Mexico (UNM). My dissertation chair at UNM and I are conducting a research study to evaluate the treatment decision-making processes among Black men who received prostate cancer treatment in southern California. We believe that input is needed from the men themselves to help us better plan and implement appropriate care for this group of individuals. *If you would like to take part in this study, can you please call me using my contact telephone number: 760-470-3939?* Once you and I connect over the phone, I will ask you several screening questions, and then an appointment can be scheduled to discuss the study with you, answer your questions and invite your participation.

Who are the researchers? The researchers include, Linda Ottley, NP-C, PhD candidate and Jennifer B. Averill, PhD, RN, Associate Professor and L. Ottley's dissertation chair, University of New Mexico, College of Nursing.

What is the purpose of this study? The purpose of this research is to describe the treatment decision-making processes of Black men and to give Black men a voice by inviting them to share their perspectives.

What does the research involve? If you decide to take part in this research you will be asked to participate in an individual interview with me at a time and location that is convenient for you. The interview should take approximately 30-45 minutes. It holds open-ended questions that have been selected ahead of time about your beliefs, attitudes and treatment decision-making processes.

Am I required to participate in this research? No, you are not required to do so. Your participation is voluntary, and no records are kept on individuals who do or do not participate. There is no penalty for declining to participate, and nothing will interfere with your care or treatment.

Will I be exposed to any experimental drugs or treatment? No. There are no experiments or treatments involved in this study.

Are there benefits to participating in this research? There are no direct benefits to individual participants for taking part in the research. However, an important benefit of the study is its potential to empower Black men to actively participate in their prostate cancer treatment decisions. This study will help us to understand how Black men make their decisions about their prostate cancer treatment to improve the quality of their care.


Are there any risks in participating in this research? There is a potential risk that interview questions may make you uncomfortable talking about this issue. In addition, there will be a slight

loss of time since the interviews can last for approximately 30-45 minutes. You may decline to answer, or you may withdraw from the study at any time without penalty.

How will my privacy and confidentiality be protected? The research has undergone a thorough ethical and peer review process conducted by UNM's Human Research Protections Office (HRPO) for any research involving human beings. Your name will be kept confidential along with transcripts, researcher's notes and tapes of the interviews. Each interview document will be assigned a random code number distinct from all the others, so that information for analysis is identified by a number, never by a person's actual name. Identifying information until the study is completed and defended as a dissertation. After this time, the consent forms, transcripts and research notes will be destroyed by shredding. If the study results are published, it will be in such a way that individual participants would not be identified except by an alias that has no resemblance to their actual identity.

We are available by phone or email to answer any questions you may have regarding your decision to participate. If you have any questions about the study, please feel free to contact me (Linda Ottley), at 760-470-3939, lottley@salud.unm.edu or Dr. Jennifer Averill, at 505-379-6159, javerill@salud.unm.edu. In addition, contact information for the UNM HRPO/IRB office will be part of the consent form, so that anyone with questions about the conduct of the research may contact a person in that UNM office. Thank you very much for considering this opportunity to participate.

APPENDIX C:
CONSENT LETTER

 **UNM HEALTH SCIENCES CENTER**

*Human Research Review Committee
Human Research Protections Office*

May 17, 2018

Jennifer Averill
JAverill@salud.unm.edu

Dear Jennifer Averill:

On 5/17/2018, the HRRC reviewed the following submission:

Type of Review: Initial Study
Title of Study: A Qualitative Examination of Prostate Cancer Treatment Decision-Making among Black Men

Investigator: Jennifer Averill
Study ID: 18-193
Submission ID: 18-193
IND, IDE, or HDE: None

Submission Summary: Initial Submission

Documents Approved:

- Averill-Ottley RecruitmentHandout (002).pdf
- Averill-Ottley HRP 581
- PI-signed interview consent letter-Averill-Ottley.pdf
- Averill-Ottley-Interview GuideHRPO (002).pdf

Review Category: EXEMPTION: Categories (2) Tests, surveys, interviews, or observation

Determinations/Waivers: Provisions for Consent are adequate.
HIPAA Authorization Addendum Not Applicable.

Submission Approval Date: 5/17/2018
Approval End Date: None
Effective Date: **5/17/2018**

The HRRC approved the study from 5/17/2018 to inclusive. If modifications were required to secure approval, the effective date will be later than the approval date. The "Effective Date" 5/17/2018 is the date the HRRC approved your modifications and, in all cases, represents the date study activities may begin.

Because it has been granted exemption, this research is not subject to continuing review.

The University of New Mexico • MSC08 4560 • 1 University of New Mexico • Albuquerque, NM 87131-0001 • Phone 505.272.1129 • Fax 505.272.9003 • hrc.unm.edu • www.unm.edu/research/hrcc
BMSB 071

Page 1 of 2

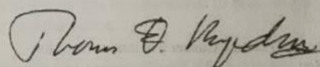
Please use the consent documents that were approved by the HRRC. The approved consents are available for your retrieval in the "Documents" tab of the parent study.

As a reminder, it is the responsibility of the principal investigator to ensure that amendments must include a plan to re-consent subjects.

This determination applies only to the activities described in this submission and does not apply should you make any changes to these documents. If changes are being considered and there are questions about whether HRRC review is needed, please submit a study modification to the HRRC for a determination. A change in the research may disqualify this research from the current review category. You can create a modification by clicking Create Modification / CR within the study.

In conducting this study, you are required to follow the Investigator Manual dated April 1, 2015 (HRP-103), which can be found by navigating to the IRB Library.

Sincerely,



Thomas F. Byrd, MD
HRRC Chair

APPENDIX D:
LETTERS OF SUPPORT



Derrick Lockett
Destiny Six Financial Services
6904 Federal Blvd.
San Diego, CA 91945
619-825-9560

April 18, 2018

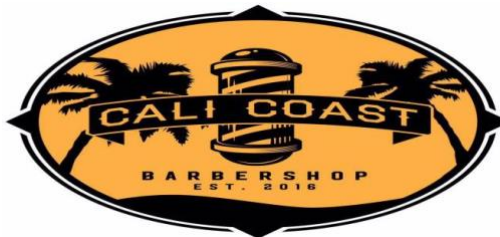
To the University of New Mexico Human Research Protection Board:

This is a letter of support for student investigator, Linda Ottley, NP-C, PhD candidate, and her primary investigator, Jennifer Averill, PhD for Ms. Ottley's study, A Qualitative Examination of Prostate Cancer Treatment Decision-Making among Black Men. I give my permission for Ms. Ottley to recruit my customers and to place recruitment flyers in my office for recruitment of participants in her study.

Feel free to contact me if you have any questions.

A handwritten signature in blue ink, consisting of a stylized, cursive 'D' followed by a horizontal line and a flourish.

Derrick Lockett



STEVEN GRAY
OWNER / IMAGE ENHANCER
6934 FEDERAL BLVD
LEMON GROVE CA 91945
619.241.9826

April 15, 2018

To the University of New Mexico Human Research Protection Board:

This letter of support is for student investigator, Linda Ottley, NP-C, PhD candidate, and her primary investigator, Jennifer Averill, PhD for Ms. Ottley's study, A Qualitative Examination of Prostate Cancer Treatment Decision-Making among Black Men. I give my permission for Ms. Ottley to recruit my customers and to place recruitment flyers in my office for recruitment of participants in her study.

Best,

A handwritten signature in blue ink, appearing to read 'S. Gray', is written in a cursive style.



African Methodist Episcopal 7515 Cuvier St., La Jolla, CA 92037 (858) 459-0271 www.princechapelame.org

April 15, 2018

To the University of New Mexico Human Research Protection Board:

This letter of support is for student investigator, Linda Ottley, NP-C, PhD candidate, and her primary investigator, Jennifer Averill, PhD for Ms. Ottley's study, A Qualitative Examination of Prostate Cancer Treatment Decision-Making among Black Men. I give my permission for the recruitment of members of my congregation at Prince Chapel by the Sea African Methodist Episcopal Church in La Jolla, California.

Best,

Reverend Larry J. Holloway, Pastor



Rev. Charles E. Price, Sr., Pastor

April 13, 2018

To The University of New Mexico Human Resources Research Protection Board:

This is a letter of support is for student investigator, Linda Ottley, NP-C, PhD candidate, and her primary investigator, Jennifer Averill, PhD for Ms. Ottley's study, A Qualitative Examination of Prostate Cancer Treatment Decision-Making among Black Men.

I give my permission for the recruitment of members of my congregation at Second Missionary Baptist Church in Oceanside, California.

In Christ Jesus,

Rev. Charles E. Price, Sr., Pastor

A handwritten signature in black ink, appearing to read "Rev. Charles E. Price, Sr.", with a long horizontal flourish extending to the right.

APPENDIX E:
INTERVIEW GUIDE

How do you feel about your prostate cancer diagnosis and treatment?

How did you make your treatment decision?

Did you trust your treating provider? Why or why not?

Do you think he or she influenced your treatment decisions? If so, how?

How do you view the treatment decision-making process?

Do you feel that you were included or had a choice in your prostate cancer treatment decision?

Did your provider listen to you and understand your concerns about treatment and side effects?

Where did you receive most of your information about prostate cancer when you were initially diagnosed and if where they easy to understand?

Did you feel that the provider respected your opinions?

Are you happy with your treatment decision?

How can the VA improve the decision-making process among Black Veteran diagnosed with prostate cancer?

Who or what was most helpful to you when making your decision?

Do you feel that you had enough time to make your treatment decision?

What else do you think I should know about your experiences?

APPENDIX F:
DEMOGRAPHIC QUESTIONS

1. When were you diagnosed with prostate cancer?
2. What type of treatment did you receive?
 - a) Surgery
 - b) Radiation
 - c) Watchful Waiting
 - d) Active Surveillance
 - e) No Treatment
3. Where were you born?
4. What is your age?
5. What is your marital status
 - a) Married or living with significant other
 - b) Single
 - c) Divorced
 - d) Widowed
6. What is your highest level of education?
 - a) 8th grade or less
 - b) High school diploma or GED
 - c) Some college
 - d) Associates degree

e) Bachelor's degree

f) Graduate or post graduate degree

7. What is your occupation?

8. What is your religion?

APPENDIX G:
PETITION FOR EXTENSION



July 9, 2019

Linda Ottley
lottley@salud.unm.edu

Dear Ms. Ottley:

I have reviewed your petition and supporting documents requesting an extension of the five-year limit for completion of a doctoral degree. Your petition for an extension through **Fall 2019** is approved. Please check with your department for deadlines appropriate to graduation. If you are not able to meet this deadline you *may be required to re-take your doctoral comprehensive examination*. I wish you continued success with the completion of your degree.

A copy of this letter is being forwarded to your department for your file. If you have any questions, please contact the graduate advisor in your department or Robben Brown, Academic Affairs Specialist in Graduate Studies (rbaca@unm.edu or 505-277-7398) for further clarification.

Sincerely,

A handwritten signature in grey ink that reads 'Julie Coonrod'. The signature is written in a cursive, flowing style.

Julie Coonrod
Dean of Graduate Studies

Cc: Nursing

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