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The Role of Religion in Mitigating Cancer Disparities Among Black Americans

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The Role of Religion in Mitigating Cancer Disparities among Black

Americans

by

Samar Hennawi

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Government and International Affairs
College of Arts and Sciences
University of South Florida

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Furthermore, I would like to thank my participants for giving me the time and valuable information needed for this research. They shared their personal stories with me and answered my questions with utmost kindness. I also want to thank my beloved children Danya and Khalid Shakfeh for editing the dissertation chapters. Finally, I would like to thank all my family, friends and colleagues for the endless support and encouragement they gave me throughout my work on this dissertation.

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Abstract

The long history of racism has created cultural barriers that prevent some Black Americans from seeking cancer treatment. Fatalism, physician mistrust, low levels of social support and self-efficacy, are the most cited cultural barriers in the literature. Black Americans' religious beliefs and church involvement have historically helped them in their struggle against racism. A quantitative and a qualitative comparison studies examine the role of Black cancer survivors' religious beliefs in their fight against cancer. The quantitative comparison study finds no difference in the cultural attitudes between Black and White cancer survivors. However, the qualitative comparison study between the same two racial groups finds Black survivors' religion reduced their fatalism and increased their levels of physician trust, social support, and self-efficacy. The research concludes that Black Americans' religion can mitigate cultural barriers that prevent some Black Americans from seeking cancer treatment.

Introduction

"I felt shame. I felt like, why me? I thought I was too good to get sick." Those were Jenny's first words when she learned about her diagnosis. Jenny, whose name was changed to protect her privacy, could not believe her diagnosis initially, and thought that her doctor mixed her up with somebody else. When she realized that she had cancer, she felt like her world was falling apart. *"I hear it is like death."*

Jenny's reaction was not unique. Other Black Americans whom I interviewed described their initial reaction as "shell shocked", "freaked out", or "scared." One interviewee refused to answer her doctors' phone calls because she was too scared to hear the word "cancer."

Cancer claims the lives of 1600 Americans everyday (Reedy & Youl, 2015), and it is the second leading cause of death in the United States after heart disease (Watson, 2015). As such, it is understandable why a cancer diagnosis triggers anxiety among stricken patients. The cancer death rate is not spread evenly among the various segments of the diverse American population. Black Americans, for example, have a higher death rate than any racial and ethnic group in the United States (Center for Disease Control, 2015).

Attempts to close the disparities in cancer death rate have yielded modest improvements in preventive screening and early diagnosis (American Cancer Society, 2015). Treatment rates, however, remain lower among Black than White Americans. It is widely believed that a variety of factors hinder Black Americans explains the persistence of cancer disparities. Black Americans face a combination of structural and cultural barriers that hinder their ability to receive cancer care. Structural barriers are the social and economic systems that disadvantage Black patients. Specifically, the American health care system, which comprises of insurance companies and providers, such as physicians, as well as the processes of referral and payment for medical services, create barriers for Black cancer patients.

Cultural barriers are the norms and expectations that hinder Black patients from receiving adequate care. They emanate from beliefs that some Black Americans hold about cancer diagnosis and treatment. Such beliefs include the belief that God wills cancer so there is no point in treating it. Individuals who hold this belief view cancer as a death sentence that cannot be treated. These beliefs are the product of exploitation of Black Americans for hundreds of years, and they prevent Black cancer patients from obtaining adequate and timely treatment (National Cancer Institute, 2008).

However, the literature tells a different story. It indicates that cancer is a treatable condition, and Black cancer survivors who receive adequate and timely treatment have similar outcomes to White cancer survivors. The American Cancer Society, which has been working on mitigating cancer disparities among Black patients since at least the 1980s, commissioned Dr. Harold P. Freeman to experiment with a Navigation program

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in an attempt to improve cancer outcomes. In 1990, Dr. Freeman launched such a program at a Harlem Hospital in New York City. He recruited two groups of minority patients, mostly Black women with breast cancer. Dr. Freeman provided the first group with navigation services and compared its outcomes to the second, non-navigated, control group. Navigation services included early diagnosis, timely treatment, and follow up care. The program reduced navigated patients' cancer stages and doubled their survivor rates in comparison to the non-navigated patients (Freeman & Rodriguez, 2011).

Following this impressive success, several Patients Navigation Programs (PNPs) began providing early diagnosis and treatment to minority populations. A PNP is a proactive approach that promotes access to timely cancer diagnosis and treatment by ensuring a seamless coordination of care and services (Freeman, 2006). PNPs assist disadvantaged cancer patients with appointments, insurance, and transportation. PNPs have made some progress in closing the disparities in screening and early diagnosis, but more work is needed to encourage cancer patients to overcome cultural barriers and seek treatment (American Cancer Society, 2015). This dissertation investigates the cultural beliefs that interfere with Black cancer patients' ability to seek treatment, and how such beliefs can be changed to mitigate the cancer disparities among Black patients.

I chose this dissertation topic after a discussion with Dr. Dawood Sultan, a courtesy professor at the University of South Florida College of Public Health. Dr. Sultan, who focuses on health disparities among Black Americans, stressed the need to

understand why some Black cancer patients do not receive treatment after a confirmed cancer diagnosis. He cited the mitigation of cancer disparities among minority populations as an objective of the Healthy People 2020 program, which aims to reduce health disparities among racial and ethnic minorities in the United States (Healthy People, 2020, 2014). The findings of this dissertation fall in line with the Healthy People Program objective in reducing cancer disparities among Black Americans.

My first inclination to conduct the research was to interview Black cancer patients who are not receiving cancer treatment and compare their responses to responses of White participants who were treated for the same cancer diagnoses. The purpose of the interviews was to elucidate differences in attitudes about cancer diagnosis and treatment between Black and White patients. Given that poverty is more prevalent among Black than White Americans (McCartney & Bishaw, 2013), I decided to recruit participants from locations that potentially serve higher percentage of Blacks, such as food pantries, subsidized housing, and community health centers in both Hernando and Hillsborough Counties. I also tried recruiting study participants from Black churches and from requesting referrals from Black friends and colleagues.

Finding Black participants in Hernando County was not easy, as Blacks in Hernando County constitute only 5.7 percent of the total county population (United States Census Bureau, 2015). Therefore, the cancer population is understandably much smaller, not to mention the segment that is not receiving any treatment. With no participants coming forward over a period of three months, I decided to change my sample population based on the advice of Dr. Richard Roetzheim, the director of

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research for the University of South Florida Department of Family Medicine. Dr. Roetzheim suggested that I obtain data on cultural beliefs about cancer from Black cancer survivors who did receive treatment, then compare their cultural beliefs of White cancer survivors.

I recruited all participants, Black and White, from Hernando County physicians' practices in gynecology, urology, and oncology over the course of six months, with the exception of two participants whom I recruited from the Hernando County Health Department and the USFTalk online forum. Upon receiving the Institutional Review Board's letter approval letter, the practices' office staff searched their billing records for services provided to patients with cancer diagnoses. The staff contacted eligible patients, explained the research topic to them, and provided them with my contact information.

As I conducted my interviews with study participants, I noticed a striking difference between Black and White participants' discourse on cancer. Black participants made many references to God while White participants hardly made any. Black participants talked about praying and asking God for guidance in dealing with cancer, and White participants talked about reading and consulting with their physicians about the best approach in handling the disease. Black participants attributed their healing to God, while White participants attributed their healing to the advances in medical knowledge about cancer. The significance in Black survivors' responses is that they contradict the belief that cancer is a death sentence and there is no point in treating it. The responses also suggest that cultural barriers relating to the belief about God as

the one who wills cancer can be removed by instilling a belief that God can heal cancer. The following dissertation chapters explain the process that lead to such a suggestion. The chapters discuss the following topics:

Chapter One starts with detailed statistics on the current disparities in cancer incidence and death rates for the various cancer types, followed by an explanation about the objective and significance of the research in devising strategies that help Black cancer patients close such disparities. The chapter then proceeds to explain the past and persistent racism that shaped these disparities.

Racism against Black Americans followed three different paradigms that corresponded with the prevailing social and political environments throughout the country's history. First, there was the dominative racism paradigm, which prevailed during the slavery era. As the name suggests, racism during this era consisted of White planters' domination over Black slaves' bodies and health. It manifested in depriving slaves from basic health care services as well as in subjecting them to medical experimentation.

The aversive paradigm followed the dominative paradigm as it prevailed between period of Reconstruction (1920s) and Civil Rights Era (1960s). After the emancipation of slaves and the rise of the capitalist economy, Blacks were no longer the source of free labor. The White social and political class viewed them as an unwanted racial group. Therefore, it excluded them from the fledgling economy and health care system, and undermined the potential of the Black medical profession. Undermining the Black medical profession coupled with the rise of White modern medicine during the aversive

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paradigm left the Black population dependent on White doctors. The White medical profession, which held a similar view about Blacks as the general White population, conducted a wide range of sterilizations and experimentations on the Black population.

Blacks' struggle for equal civil rights, which culminated in a series of Supreme Court rulings against segregation, ended the aversive paradigm in the 1960s. The result was a significant improvement in their socioeconomic statues, which translated into improvements in their general health. Ending segregation meant better living and working conditions, and higher wages meant better food quality and less anxiety about meeting basic needs. However, despite the improvements in health status, cancer incident and mortality rates remained high among Blacks compared to Whites (The Malone Heckler Report, 1985).

The Rise of the systemic racism paradigm undermined Blacks' newly gained equality. Systemic racism commenced with election of Ronald Reagan and continues to disadvantage Black Americans today. Health care in the systemic racism paradigm is characterized by the continued undermining of the Black medical profession, structural and cultural barriers that often leave Blacks with lower quality, and harder to access health care services. Consequently, many Black cancer patients do not receive adequate and timely treatment as of the writing of the present study.

Chapter Two reviews the literature on attempts to close the cancer disparities between Black and White Americans. It starts with highlighting the *Malone Heckler Report* findings, which brought to light the persistent cancer disparities between Black and White patients. Then the chapter examines the role of Patient Navigation Programs

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(PNPs) in reducing cancer disparities among Black Americans. As the chapter finds that PNPs have not increased treatment rates among Black cancer patients, it moves to discussing the role of faith in mitigating cultural barriers. Focus on faith comes after noting that three out of the four most cited cultural barriers are rooted in the religious beliefs of some Black individuals: Fatalism, social support, and self-efficacy. Finally, the chapter discusses the role of churches in addressing the cultural barriers in their congregations. This raises the question that if cultural barriers were removed, would cancer disparities be eliminated, which is answered in Chapters four and five.

Chapter Three reviews the research methodology and the basis of research. The research is based on postpostivsim, which questions the conventional knowledge that all Black Americans have cultural beliefs about cancer that are different from White Americans' beliefs. The conventional knowledge implication is that removing cultural barriers will not change Black Americans' beliefs about cancer. This dissertation theorizes that removing cultural barriers changes Black cancer survivors' beliefs to become like White cancer survivors' beliefs. It hypothesizes the following:

1. If Black Americans cancer survivors receive treatment then they are equally as fatalistic as White Americans.

2. If Black American cancer survivors receive treatment then they trust their physicians as much as White Americans do.

3. If Black American cancer survivors receive treatment then they have equal levels of social support as White Americans.

4. If Black American cancer survivors receive treatment then they have equal levels of self-efficacy as White Americans.

To conduct the research, I recruited 15 Black, and 15 White cancer survivors to compare their beliefs about cancer. After controlling for age, gender, and cancer type, I conducted face-to-face interviews with the survivors and asked them a series of survey questions for a combined qualitative and quantitative research design. The quantitative survey instruments were Powe's fatalism scale, Freburger's physician trust scale, the Modified Duke-UNC Functional Support scale, and the CASE-cancer self-efficacy scale.

The Qualitative survey questions were designed to reveal interviewees' cultural beliefs about cancer and were based on literature reviews on Black Americans' cancer beliefs. All the scales have already been tested for validity and reliability. Finally, I conducted an unpaired t-test to compare Black and White interviewees' answers of the quantitative survey instruments, and a Constant Comparison Method to qualitatively compare interviewees' answers.

Chapter Four answers questions from chapter Three by conducting an unpaired t-test on Black and White cancer survivors after controlling for socioeconomic factors, cancer types and stages, and logistical barriers. The research analysis assumes that cancer disparities do not exist among cancer survivors who do not have the cultural barriers mentioned in Chapter one. With this assumption, the research hypothesizes that Black cancer survivors who receive treatment have the same levels of fatalism, physician trust, social support, and self-efficacy as White cancer survivors. After obtaining survey responses from all participants on fatalism, physician trust, social

support, and self-efficacy, the unpaired t-test finds no significant differences in the cultural attitudes between Black and White cancer survivors. This finding falls in line with the assumption that cancer disparities do not exist among Black and White cancer survivors with similar cultural attitudes towards cancer.

Chapter five further investigates Black cancer survivors' cultural attitudes through a qualitative analysis. The first section of the chapter narrates detailed accounts of the Black and White research participants' experiences with the cancer diagnoses and treatments. The second part of the chapter compares Black and White participants' responses using the Constant Comparison Method. The comparison shows that Black participants make many more references to religion than White participants. The qualitative analysis indicates that Black participants' religiosity boosted their levels of physician trust with the belief that physicians are the means through which God heals. It bolstered their self-efficacy by teaching them to trust God and be grateful to him. Finally, Black participants' religiosity and involvement in church increased the levels of social support and expanded the sources of support they received while dealing with cancer.

Finally, the Conclusion chapter synthesizes the information from all the chapters and draws inferences about the treatment gaps among Black Americans. The chapter concludes that religiosity plays a positive role in shaping Blacks' cultural attitudes towards cancer diagnosis as it serves as a motivator to seek treatment among Black cancer patients. This finding suggests that religion can be a positive force in increasing treatment rates among Black cancer patients. The chapter also concludes that the Black Church, which has historically improved cancer-screening rates among its congregation

members, can improve their treatment rates as well. The Church provides a venue for survivors to share stories about their experiences with cancer diagnoses and treatments. These stories encourage current and future Black cancer patients to break the cultural barriers that prevent them from seeking treatment.

While this dissertation offers a nuanced understanding of the role of religion in shaping Blacks' cultural attitudes towards cancer, it has several limitations. First, it bases its results on cancer survivors who have received successful treatment. Therefore, these results are not applicable to Black cancer survivors who do not receive treatment. Second. The, small, self-selective, non-randomized, population sample limits the applicability of the study to the entire Black American population. Third, its findings may not be applicable to populations of other faiths, nor does it consider the various denominations within the same faith. Finally, the study bases its findings on patients with only early stages of cancer. Further studies may shed light on Black Americans' cancer cultural attitudes.

Chapter One

The Making of Black American Cancer Disparities

I. Introduction

The Center of Disease Control and Prevention (CDC) has been monitoring cancer disparities among Black Americans since 1990s. The CDC initiated the Healthy People Program in order to provide science-based, national goals and objectives, with ten-year targets that include lowering the cancer incidence and mortality rates among Black Americans. The higher incidence and mortality rates are the result of long standing racism against Black Americans. Over the past four hundred years, Black Americans have endured various forms of racism that created unhealthy environments, with high rates of disease exposure and countless assaults on the health integrity of their bodies. These forms of racism against Black Americans have evolved over time in response changes in the political environment. This chapter explains how the various political environments the United States' history produced racism paradigms that endangered the lives of Black Americans, created health disparities between Black and White Americans, and undermined the Black medical profession.

II. The Disparities in Cancer Incidence and Death Rates

Cancer afflicts Black Americans with a higher death rate than White Americans. For all cancer types, the death rate is 31 percent higher among Black American males, and 15 percent higher among Black females than Whites. For prostate cancer, the most common type among males, the death rate is 31.4 percent higher among Black Americans than Whites. Black American women have a 10 percent higher mortality rate than White women despite the fact that they have a 5 percent lower incidence rate (American Cancer Society, 2013).

The most significant disparities are in Kaposi sarcoma (KS), stomach cancer, and multiple myeloma, where Black Americans have about twice the incidence rate compared to White Americans. In contrast, the least disparities are in esophagus cancer for men, and uterine cancer for women (0.4 and 0.6 percent respectively). Notably, Black American women and men have a much smaller incidence rate of skin cancer than Whites. Black men are 26.1 percent less likely to develop skin cancer than White men, and Black women are 16.8 percent less likely to develop skin cancer than White women (American Cancer Society, 2013).

The five-year survival rate is the standard for measuring the progress of cancer. Black Americans' five-year survival rate has improved from 27 percent in the 1960s to 60 percent in (2008). However, it still falls short of the Whites' five-year survival rate of 69 percent. For colorectal cancer, the third most common cancer among Black Americans, the five-year survival rate is lower at each stage of diagnosis compared to Whites, 57 percent to 65 percent. For cervical cancer, which is one of only two

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preventable cancers, the five-year survival rate is 59 percent for Black American women compared to 69 percent for White women (American Cancer Society, 2013).

Delayed diagnosis and treatment are the main reasons behind higher cancer incidence and death rates. Black American women are more likely to be diagnosed with late stage breast cancer than any other racial group (Magee-Gullate et al, 2010). For all types of cancer, Black American women and men are more likely to be diagnosed with larger size and later stage regional tumors compared to White women and men (Jemal, et al 2010).

III. The *Healthy People* Initiative to Reduce Cancer Disparities

The Healthy People initiative began in 1979 to track and improve Americans' social determinants of health, which refers to the non-biological factors, including living conditions and eating habits, that impact individuals' health. Enhanced understanding of the social determinants of health in the 1960s, culminated in the creation of the Disease Prevention and Health promotion office (DPHP) in 1976. DPHP worked under the auspices of the Department of Health and Human Services and the Center for Disease Control and Prevention (CDC) to design and implement social and political programs that support changes in the population's health behavior and health environment (Green & Allegrante, 2011). To that end, the DPHP launched its *Healthy People* Initiative to provide science-based, national goals and objectives, with 10-year targets to guide disease prevention efforts (Center for Disease Control and Prevention, 2013).

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In 1985, the Department of Health and Human Services released its first report on Black and minority Health. The report brought to light the extent of disparities in cancer and other chronic disease between the Black and White populations (Nickens, 1986). Since then, the *Healthy People* program has been tracking the progress in health status of Black Americans and other minorities. In addition, the report prompted the Department of Health and Human services to create the Office of Minority Health which focuses on closing disparities by engaging multiple sectors to take actions that facilitate reaching Healthy People goals (Office of Minority Heath, 2011).

The *Healthy People* program set its objectives to reduce cancer disparities among Black Americans (known as *Healthy People 2020*). These objectives include: Objective AHS-6.2, which is to reduce the proportion of persons who are unable to obtain, or delay in obtaining, medical care from 4.7 percent to 4.2 percent by 2020; Objective C1 to reduce Black American cancer death rate from 203.0 to 161.4 per thousand by 2020; and Objective C13 to increase the proportion of 5-year Black cancer survivor rate from 66.2 to 72.8 percent (Healthy People 2020, 2016).

Cancer disparities among Black Americans can only be understood in the context of racism. Since their arrival on American soil, Blacks have endured social environments that produced forms of racism that endangered their health with higher rates of exposure to diseases and assaults on the integrities of their bodies. Each form of racism falls within a particular paradigm that corresponds with a different social and political era in the American history.

IV. Paradigms of Racism

In his classic work, *White Racism: A Psychohistory* (1984), Joel Kovel categorizes patterns of White American racial attitudes towards Blacks from colonial times until the latter decades of the twentieth century as *dominative, aversive, and systemic-racism paradigms*. The *dominative racism* paradigm of the Plantation system during the slavery era was marked by direct physical oppression. The *aversive racism* paradigm of precluding Blacks from participating in the political, economic, and social life that White Americans enjoyed through strict structural segregation in all facets of society, from housing and schools, to medical facilities and armed forces units. Finally, the *systemic racism* (also called meta-racism) paradigm hinders Blacks from attaining equal economic and social status to White through social structures. Unlike the previous two paradigms of overt racism, which engaged the human agent, systemic racism is a covert form of racism. The three paradigms are not mutually exclusive. While each paradigm prevailed during a different era in American history, elements of the other two paradigms are still present.

1. The Dominative Paradigm

The Dominative paradigm, which prevailed during the slavery era, began as White masters brought Black Slaves from Africa to exploit their labor on the plantation. Racial thought of the slavery era provided several arguments justifying servitude of Black people (Byrd & Clayton, 2000, 60). The first argument invoked long-held Biblical interpretations of Noah's curse on Ham's descendants. Antebellum southerners

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believed that by enslaving Negroes, the descendants of Ham, they were carrying out God's will. For slave-holding planters, the sexual transgression of Ham against his father was indicative of his deviant sexuality, worthy of eternal degradation. Accordingly, his descendants were considered equally deviant (Haynes, 2002, 67). Thus, White Southerners, who saw themselves as God's virtuous children, felt quite comfortable fulfilling His punishment on Black people.

The erosion of formal religion and the rise of science in the late nineteenth century paved the way for the emergence of the pseudo-scientific racial theory of "biological determinism" providing the second justification for slavery. Based on cranial measurements and observations of physical traits, the theory posited the permanence of all race characteristics regardless of environmental changes or even interracial "breeding" practices. This theory was consistent with the existing idea of species evolution, which ranked the Negro race a notch above chimpanzees and below the fully advanced White European race (Banton,1998, 58). Southern planters welcomed the new findings postulated by biological determinism as they cemented the concept of Black inferiority because it justified their domination over Black slaves.

Contrary to the White planters' position, however, non-slave holding Whites in the North disliked the concept of biological determinism. As the number of non-slave holding Whites increased following the extension of suffrage to non-property owning White males in the 1830s (Banton, 1998, 61), some White workers became active in the Abolitionist Movement aimed at ending slavery and sending Blacks back to their original lands.

Southern planters responded by positing a third justification for slavery. Thriving on the economics of free-labor provided by slaves, Southern planters painted a positive image of the patriarchal plantation economy. They contended that Black slaves were unable to fend for themselves and that slavery was their only hope for survival. Some planters went to the extreme of arguing that if Whites were unable to care for themselves in the northern capitalist system, then the less intelligent Blacks certainly needed their masters to care for them. They painted the image of Backs as childlike creatures who needed constant guidance, supervision, and even discipline from their White masters (Byrd & Clayton, 2000, 258).

A. Black Slaves' living and Working Conditions

White planters controlled the lives of Black slaves in every aspect including their bodies and their health. They bought Blacks as chattel to be used as a means of cotton production when cotton was the main driver of the Southern economy. Slave owners extended the concept of property to the health of their slaves by objectifying their health and reducing it to a calculated variable, such as age, years of servitude, and expected number of years left in slave lives. Slave health objectification allowed planters to tie health conditions to the amount of slave labor required for maximum profit. Planters looked for slaves with sound health, those who could provide the largest amount of labor under extreme conditions. The need for "sound" slave health required planters to establish dominance over all economic aspects of slave life, beginning from the point of purchase and extending beyond the end of chattel slave life.

Buyers purchasing slaves engaged in intimate inspections of slaves to ascertain the soundness of their health. They looked for physical and mental health signs that could be potential hindrances to the arduous labor expected of slaves. With the help of hired doctors, they probed for signs of chronic diseases and mental conditions by examining slaves' scars and other marks that indicated past medical treatment. Possession of sound mental conditions, measured by the degree of submission and compliance, was a major determinant in the price of a slave. Buyers looked for signs of past defiance. They interpreted whiplash scars, missing toes, chopped ear lobes, and other injuries as signs of past and potential future defiance (Fett, 2002, 21).

The reproductive health of slave women was of particular interest to planters. Slave women of childbearing age were sold for twice the price of those past their child-bearing years. This was particularly true for women labeled as "fast breeders" (Byrd & Clayton, 2000, 282). Thomas Jefferson once declared, "I consider a slave woman who breeds once every two years as profitable as the best worker on the farm." Planters typically maximized their profits from slave women by forcing them into sexual relations with several men at an unhealthy age, and by personally impregnating them (Washington, 2006, 44).

Planters imposed health-endangering daily labor routines on their slaves by demanding treacherous work under extreme weather conditions. Working hours began before sunrise and ended with the fall of darkness. On moonlit nights, working hours were extended until the next morning. Slave labor included direct contact with cattle, pigs and goats, through skin, open wounds and infected carcasses, increasing their

exposure to diseases such as malaria, brucellosis, mud fever, and anthrax (Semmes, 1996, 35). Accidents and environmental hazards took a heavy toll on the health of slaves as well. Falls, sun strokes, frostbite, overturned carts, runaway wagons, drowning, limbs caught in farm machines, kicks from animals, cuts from axes and blades, were common types of injuries (Savitt, 2007, 67).

The use of whips was an integral part of daily slave life. Whipping inflicted permanent injury upon its victims. Laying stripes across the bare back and buttock caused indescribable pain, especially when each whip lash dug deeper into previously opened wounds. In addition to skin, muscle, and occasional organ lacerations, whipping caused the loss of large amounts of blood, increasing the potential for infections and shock. Padding, another form of whipping, jarred every part of the body by the violence of the blow, raising blisters from repeated strokes (Savitt, 2007, 67). Though such punitive and painful punishments were a means of discipline and maintaining order, they also sent a clear message to slaves about the ultimate domination of planters over their bodies and health.

The living conditions of slaves presented further health hazards. Planters allotted enslaved men and women living quarters that provided them with little comfort. These quarters were perfect breeding grounds for a variety of ailments. Damp floors, unhygienic conditions, weather extremes, and inadequate sunlight attracted bacteria and viruses, causing the spread of flu, coughs, and infections such as malaria and tuberculosis. Overcrowding, dirty clothes, unsanitary blankets and eating utensils

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insured the quick spread of those infections. Slave community life and children's play facilitated further disease dissemination.

The proximity of slave living quarters to sewage facilities invited a host of deadly parasites that ravaged the inside slaves' bodies, inflicting them with high morbidity and mortality rates. Slaves used polluted water for eating and drinking, allowing the parasites that cause cholera and yellow fever ample opportunity to enter their intestines and bloodstreams. Compounding the problem of unhygienic living conditions, these parasites made intestinal disorders a commonplace among slaves (Savitt, 2007, 65).

The diet of slaves was a major detriment to their health, and controlling slave diet was another form of planters' domination over slave health. It affected their ability to resist disease and recover from illness and injury. Slaves, however, had no control over the quality and quantity of food allotted to them by their owners. Meals provided to slaves were usually high in calories but dangerously deficient in important vitamins and minerals. Planter gave their slaves fatty pork cuts and cornmeal. Slaves occasionally supplemented their diets by eating grains and vegetables they produced. Such food crops, however, were not always easy to obtain. Although planters allowed slaves to produce their own foods on the plantation, long working hours on the main cash crops, cotton and tobacco, consumed their time and energy, leaving little opportunity for food crop production. Thus, the combination of food shortages and poor diets contributed to an array of health problems among enslaved Blacks (Semmes, 1996, 41).

B. Medical Care for Slaves

Medical treatment of slaves was another dimension of White domination. Since planters' concern about their investments was the primary driver of medical intervention, they controlled the nature and timing of medical intervention. Planters' feared the financial loss due to slave death and disease dissemination. This fear necessitated contracting with physicians for required or emergency medical intervention. However, the slaves did not trust White physicians and their practices, and preferred home remedies. Consequently, they often hid ailments from their masters. Similarly, cost-conscious masters withheld medical treatment until they had exhausted all possible medical remedies or when surgical treatment was needed. In all cases, however, the decision to intervene in the health care for slaves was a White prerogative (Savitt, 2007, 71).

Sick slaves received care either at their lodgings, at public hospitals, or at slave hospitals located near slave markets or on the premises of plantations. Slave hospitals were old buildings where the combination of dirt, mold and moisture left a nauseating foul stench. The sick lay in agonizing pain on either wooden settles or on the floor with no mattresses or pillows. They were cared for by unsympathetic medical and nursing trainees whose primary concern was to gain experience at the expense of the training material slave patients provided. Slaves feared hospital admission, where they knew they would become objects of exploitation and experimentation. Moreover, the long working hours and cultural differences between the White medical staff and the sick Black patients exacerbated their already inferior patient care. Slaves usually had no say

in their hospital admission. White masters often admitted slaves not just for treatment, but also as a form of punishment. (Byrd & Clayton, 2000, 264-317).

C. Medical Experimentation on Black Slaves

Medical demonstration and experimentation were the most gruesome aspects of White medical domination over blacks. Medical schools opened public and slave hospitals as part of their philanthropic efforts. They encouraged planters to send sick slaves to their facilities and competed for students by advertising their wide selection of training material. Schools provided students with training for all known diseases and for operative procedures, using the legally silent Black sick. For example, a South Carolina medical school, which admitted Black patients, announced that it would treat slaves at no cost to their slave owners. This decision was based on the desire of the faculty, whose main objective was to collect as many interesting cases as possible, to benefit their students and the school (Savitt, 2007, 78).

Black patients provided White physicians with a steady stream of training material for medical and surgical experimentation. When Black patients presented with unknown illnesses, White physicians administered whatever treatments they thought appropriate regardless of the scientific merit of the treatment. Experimentation with different medications continued until a positive result was reached. Many physicians borrowed or bought slaves for the sole purpose of experimentation and justified their experiments as necessary for medical advancement. In one instance, a doctor who owned and operated a small hospital in Charleston advertised in the local paper about

his willingness to pay "highest cash price" for fifty Blacks infected with a variety of spleen, liver, and kidney diseases. In his advertisement, Dr. T. Stillman appealed to slave owners who wished to "dispose of" unwanted slaves so they could be used for experimentation. In another instance, a physician borrowed a slave from a grateful patient to test agents that increased slave heat tolerance. The physician placed the slave in a heated pit, with a temperature exceeding one hundred degrees, while administering different medications, to test which medication gave the slave the most resistance to heat. The physician later subjected the same slave to bleeding and blistering experiments and tested the blistered slave every other day to ascertain how deep black skin went (Savitt, 2007, 86).

Physicians earned fame by publishing their experimentation methodologies and results in medical journals. Dr. Marion Sims earned the nickname "father of American gynecology" by experimenting on slave women with vesicovaginal fistulas. Sims borrowed eleven slave women from their masters with the promise to cure the women of their conditions. Showing no respect for their dignity and privacy, Sims made his totally naked human subjects kneel on their hands and knees and inserted a special speculum inside the vagina to gain full view of the fistula. Sims acknowledged his lack of experience in the field. He only became interested in the condition after inflicting a vaginal injury to a laboring slave woman and causing death to her fetus while applying forceps (Savitt 2007, 86) .

To repair the vesicovaginal fistula, Dr. Sims performed a terribly painful surgery on his subjects. Not only did he have to close the unnatural openings in the vaginal

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tissue, he made the edges of the opening knit together by abrading the skin on the edges of the cavity every time. He then closed the edges with sutures and saw them get infected and reopen, again and again. Dr. Sims finally perfected the procedure after many attempts on his subjects. Some patients underwent the harrowing procedure thirty times (Savitt 2007, 87).

Dr. Sims refused to anesthetize the agonizing women during the procedure despite their bone-chilling shrieks and appeals for relief. He claimed that Black people did not feel pain the way White people did. Instead, as a strategy to control the behavior of his subjects, he subdued them with large doses of opium after the surgery, sometimes for several weeks at a time. He followed this strategy as a means to control his subjects' behavior. The resulting addiction to morphine weakened the women's will to resist repeated procedures.

Marion Sims became a celebrated gynecologist following his success with these procedures. He taught medicine in New York City where he conducted experiments on Black and immigrant patients. He held many influential positions in hospitals, and various medical societies. Sims founded the first women's hospital in the country. His reputation followed him across the Atlantic where he was honored by the French royal family. Several French and American women's clinics sprang up in his wake and practiced his philosophies. In illustrations accompanying his accounts of the procedures, Dr. Sims never disclosed the race of his subjects. He portrayed his patients as White women. He also never mentioned the use of morphine and the chattel slavery system through which he acquired his subjects (Washington, 2006, 63).

Dr. Sims' grisly example of medical experimentation is not unique. Other White doctors experimented on Black patients with cesarean sections, cataract surgeries, and scores of other surgical procedures that are practiced today. These procedures were typically carried out without the consent of the Black subject. Unfortunately, Black Americans have not always benefited from the procedures that they helped perfect and for which they provided valuable learning materials (Washington, 2006, 65).

Medical violence against Blacks under the dominative racism paradigm cemented Blacks' health disparities and laid the ground for Black-White medical relation. The attitudes of Black Americans towards White medicine today still carries the vestiges of Antebellum medicine in the form of deeply entrenched medical racism and Blacks' mistrust of White medicine.

2. The Aversive Paradigm

The dominative racism paradigm collapsed with the first cannon fire of the Civil War. Blacks enthusiastically welcomed the fall of the dominative paradigm by enlisting in the Union Army in large numbers to fight for their freedom. In the immediate aftermath of the war, freed Blacks gained a sense of equal status to Whites with the Freedman's Bureau Act (1866-1868), which was enacted to help former slaves make the transition to freedom. The Bureau established schools, hospitals, and negotiated labor contracts to protect freed slaves from abuse by their former masters (Benedict, 1974).

The Aversive paradigm commenced with a series of Supreme Court decisions that striped Blacks of most of the liberties they gained following the Civil War. These

laws, known as Jim Crow laws, allowed southern states to establish Black Codes restricting Blacks to living and working arrangements within specified areas. Northern states followed suit and restricted Blacks' working and living arrangements to urban ghettoes. The imposed segregation locked Blacks into a low socio-economic status by dislocating them from the country's burgeoning economic power (Smith, 1993, xiii).

A. Blacks' Living and Working Conditions

Blacks were excluded from industrial jobs because both White employers and workers opposed employing Blacks. Industrialists refused to hire Blacks because they assumed that White workers would object to working next to Black workers. White workers did whatever they could to keep Black workers off the payroll, fearing that they could lose their jobs to the abundance of Black workers willing to work for low wages. Moreover, scientific racism, which posited Blacks as an inferior race based on scientific calculations, such as head circumference, facial measurements, and arms' length, portrayed Blacks as untalented, slow to learn and unfit for the modern industrial environment.

Unions strongly opposed Black membership and made sure very few Blacks could get skilled jobs. In many industries, management and unions tacitly agreed to reserve low-skill, menial jobs for Negroes, leaving high skilled and supervisory jobs for White workers. Therefore, the majority of employed Blacks in the North held menial "negro jobs," which were stigmatized positions at the bottom of the occupational strata (Farley & Allen, 1987, 116).

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The housing segregation forced Blacks to live in concentrated small urban dwelling units. As time went by, their living conditions worsened. Overcrowded substandard housing units with decaying plumbing, paint, and structural defects decreased property values in these neighborhoods, leading to less government attention. This was evidenced by dilapidated pavement conditions, lack of streetlights, poorly maintained playgrounds, and the deterioration of neighborhood schools (Hawkins, 1976).

Refusing to conform to this new method of subjugation, Blacks entered the Twentieth Century engaged in a new phase of struggle for equality, beginning in 1917 with the increased labor opportunity brought on by Word War I. Shortly after moving to an abandoned Dutch Neighborhood in Harlem, a number of southern Blacks established the New Negro Movement, (also known as the Harlem Renaissance) a Black literary and cultural movement aimed at exploring and defining the Blacks American identity as a collaborative and a cumulative one (Barnes, 2006). The Negro Movement spread to Chicago and other major cities with large Black populations. A plethora of media outlets and civic organizations created a thriving civic culture and a solid middle class. Magazines, such as *Ebony*, *Negro Digest*, and *Jet*, gained wide popularity reaching thousands of subscribers throughout the country. These publications played an important role in raising awareness about racial inequalities and promoting a sense of Black self-help (Green, 2007, 138).

The experience of participating in wartimes endeavors had a dramatic effect on Blacks' sense of citizenship. Blacks who enlisted in the U.S. army during World War I

faced a systemic pattern of discrimination. They were kept in segregated war units under the supervision of White officers. They were assigned to menial support duties such as cooking and cleaning, because White commanders and politicians believed that Blacks were not mentally or physically fit for combat. Black recruits were never promoted into the higher ranks regardless of educational level or performance (Morehouse, 2000, 3).

During World War II, Black soldiers faced a similar pattern of discrimination. The War Department (now called the Defense Department) and the political leadership insisted that segregation did not constitute discrimination. It was a necessary strategy to maximize efficiency due to the differences in physical and mental abilities among the different races. Efficient troop utilization meant keeping Black soldiers in segregated units and keeping them in service jobs rather than assigning them to combat units (Morehouse, 2000, 3).

As they socialized with more tolerant populations, Black soldiers serving in Europe became uncomfortable with segregation. Europeans treated American soldiers equally irrespective of their color, which made Black soldiers question the legitimacy of Jim Crow laws and reject segregation as a social norm. They were further infuriated with White soldiers' attempts to transplant Jim Crow attitudes to Europe by degrading the Black race in front of Europeans. The juxtaposition of equal treatment by Europeans with the persistence of White discrimination and insensitivity increased the militancy of Black soldiers. This caused them to insist on demanding equality through integration. They realized that segregation was merely a White American strategy to prevent the

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advancement of Black people regardless of their contributions and sacrifices. Such militant responses were widely popularized by the Black printing outlets. A plethora of analyses, opinions, and editorials were published throughout this period of conflict arguing against segregation and making the case for equality between Blacks and Whites, and increasingly called for full equality in all aspects of American life (Parker, 2009, 118).

Social interaction with French civilians raised the self-esteem and the racial consciousness of Black soldiers. They received a warm welcome from French shopkeepers and merchants. The French had a favorable view of the "tan Yanks" who fought for French democracy. Reflecting on their own undemocratic system of segregation, Black soldiers returning from the war began pressing for the "equal" portion of the "separate but equal" law. This was especially true for Southern Blacks who sometimes returned to face lynching after the war (Keene, 2002).

World War II was a defining era for Blacks' struggle against racism. Members of the medical and legal professions, equipped with the necessary skills, navigated through the political system to achieve integration. Black Medical professionals achieved Blacks' first victory towards desegregation with the integration of Armed Forces' doctors and nurses through President Truman's Executive Order 9981, which ended segregation of the military. Black legal professionals won a series of Supreme Court cases that ended the aversive paradigm, and achieved full integration.

B. Blacks' Medical Care

Under the aversive racism paradigm, Blacks were excluded from the burgeoning health care industry and from the medical profession, which prevented them from attaining the care required to compensate for their health deficits. In addition, remnants of the dominative paradigms persisted in the form of medical demonstration and experimentation. What was new in the aversive paradigm was the introduction of class as a variable in racial relations. As some Blacks climbed the socioeconomic ladder, they became less sympathetic to the plight of their brethren. In some cases, they became part of the White dominative exploitive system.

Since the beginning of the 20th century, access to health insurance in America has basically only been available through employment. The meager access to White medicine southern Blacks were afforded during slavery was not available to them after the Civil War. Former planters, who rehired their ex-slaves to work in the cotton fields, had no obligation to provide any health care to their Black tenants. In many areas, doctors and nurses were unwilling to treat Black patients, and Blacks who needed hospitalization had to find a hospital that had a segregated Black facility. In general, Blacks who were sick had to rely on themselves for health care. They typically resorted to folk medicine or just hoped the ailment would cure itself (Farley & Allen, 1987, 30).

Blacks in the North didn't fare much better. Non-unionized menial jobs did not offer health benefits. Black communities were only able to obtain low quality insurance policies through fraternal orders. These policies only offered scant benefits for a limited period of time (Byrd & Clayton, 2002, 48).

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Due to poverty and proximity, city public hospitals were the only available option for Blacks in need of hospitalization. Blacks occupied segregated wards in these hospitals. The discovery of germ theory prompted municipalities and philanthropists to establish city hospitals knowing that germs do not respect a color line (Gamble, 1989, 8). For example, the Michael Reese Hospital in South Chicago was funded by the Julius Rosenwald Charitable Fund. The hospital maintained a Negro division, which supported public health and professional education programs as well as outpatient services. However, with the advent of the Great Depression, charity hospitals like Michael Reese faced fiscal challenges. These hospitals could not recover expenses from their poor, non-paying patients. Local governments used abandoned, outmoded White hospitals as public hospitals to treat the poor, including Black people, as in the case of Kansas City and St. Louis Hospitals (Gamble, 1989, 36).

City hospitals offered little, if any, improvement from the deplorable conditions of the slave hospitals. In 1927, surveyors from the College of Surgeons, at the request of the National Medical Association, conducted a survey of public and Black-owned hospitals. Segregated Black wards in public hospitals were found to be dirty, crowded and in poor repair. They were short on essential equipment and supplies, ranging from X-ray machines to linens. Hospital staff were overworked and underpaid. Therefore, they over-relied on interns for patient care. In one case, an intern was instructed to watch and care for 1000 patients (Dowling, 1982, 134).

Surveyors referred to the patient admitting process as "grossly crude." Patients and their families filled all the seats of a barn-like waiting room, and many were forced

to stand for hours. Other patients lay on stretchers in the hallways, waiting in pain for hours until they were taken care of by orderlies or interns. Many patients were sent away or dumped at other hospitals (Dowling, 1982, 138, 148).

Once admitted, patients continued to endure gross neglect from the short-handed hospital staff. They were examined in large wards divided by partitions that offered no privacy. Overworked nurses could not keep up with patient needs. They missed overflowing bladder catheters and gastric suction tubes. The scarcity of nurses also meant frequent medical errors like missed medication times or medications being given to the wrong patients. Naturally, this substandard care resulted in numerous patient deaths. Many hospitals gained bad reputations as the news media got hold of their high patient death rates. For instance, Cook County hospital in Chicago was referred to as "Misery Harbor," Lincoln Hospital in New York City was dubbed "The Butcher Shop," and Gallinger Municipal Hospital was called "Our Murder Factory" (Dowling, 1982, 147).

Black-owned hospitals throughout the United States fared no better. A black physician named Algernon Jackson was commissioned by the American Medical Association to investigate 120 Black hospitals around the country in the late 1920s. Dr. Jackson used a grading system of A, B, C, and D. Hospitals receiving a grade of D were deemed unworthy. Jackson awarded 13% of surveyed hospitals with an A and 22% with a D. He described conditions in the D-rated hospitals as so "filthy and inadequately equipped and managed that one would hesitate to drink the water in them, much less submit to even the most minor surgical operation" (Gamble, 1989, 43).

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C. Undermining the Black Medical Profession

Segregation in medicine not only had an adverse effect on Black patients but on Black physicians as well. Following emancipation, White medical schools in the South refused to admit Black students into their programs, leaving Black medical students with only a handful of choice schools in the north where they were admitted. Cognizant of the importance of Black medical professionals to the health of Black people, a few medical schools were opened around the country in the 1910s and 1920s to fill the need to graduate professionally trained Black physicians. At the beginning of the Twentieth Century, about a dozen schools were established either by White missionaries or Black physician proprietors. By then, the medical profession was riding the tide of rising scientific knowledge and asserting itself as the sole authority in health care. The newly consolidated medical authority resolved to raise medical practice standards by revising the curricula of medical schools to cover the latest innovations in diagnoses and treatments (Savitt, 2007, 252).

The American Medical Association, which was founded in 1847 as the medical profession's major representative body, created the Council on Medical Education (CME) in 1900, to evaluate the nation's medical schools. The evaluations put Black schools in a vulnerable position. These schools did not have the support of philanthropists that White medical schools had. They were entirely dependent on student tuition. Black medical students were usually poor and had to work to cover their tuition fees. Not surprisingly, the CME report was detrimental to Black schools. The report put these schools on notice based on a lack of clinical training due to an absence

of laboratories at their facilities, as well as their outdated curriculum. Black schools were also censured for offering evening classes, which allowed students to work during the daytime. Black physicians could not influence the AMA stance since they were not allowed in the exclusively White organization. These pressures forced most Black schools to close their doors by the first decade of the Twentieth Century (Savitt, 2007, 255).

A 1910 review, the Flexner Report, dealt most Black medical schools a death blow. Commissioned by the Carnegie Foundation for the Advancement of Teaching, the CME charged Dr. Abraham Flexner in 1908 with the task of evaluating the quality of medical education in the country. This evaluation was based solely on the standards of the American Medical Association (AMA). The report would be published in the Journal of the American Medical Association (JAMA), and physicians graduating from schools, which did not meet the AMA standards, would be denied a license to practice. Failing schools would be instructed to comply with the new standards or close their doors.

The Flexner Report portrayed the medical education of Blacks as deficient in five of the seven remaining Black medical schools. It noted meager equipment for chemistry, pharmacy and microscopy, as well as ill-equipped patient rooms and the absence of laboratories and clinical facilities. The report lamented the misrepresentation of the quality of curricula by some schools and poor patient record-keeping of affiliated hospitals. The Flexner Report informed readers that Black students, and by extension, Black medical practitioners who graduated from the five schools, did not receive

adequate medical education and were therefore in no position to add value to the "Negro health" (Savitt, 2007, 258).

The Flexner Report did more than describe the poor quality of Black medical schools. It prescribed a limited role for Black physicians and their potential and ability compared to their White counterparts. According to Dr. Flexner, Negro health could not be wholly left to Negro physicians, though the practice of Negro physicians was to be restricted to the Negro population. He further constrained the value of Negro physicians to the White population by suggesting that restricting their practice would prevent the spread of disease from the Black race to the White race. Finally, Flexner reduced the role of the Negro physician to practicing fundamental hygienic principles by stating that "a well taught Negro sanitarian will be immensely useful" (Savitt, 2007, 258).

Of the seven remaining Black schools, only two survived the Flexner Report. Black students wishing to obtain medical degrees were limited to Howard and Meharry Medical Schools or to the few White schools accepting Black students in the North. These limited options left the Black community with a shortage of physicians. The Great Depression compounded this problem by negatively affecting the number of Black medical student graduates (Savitt, 2007, 266). Though medical school segregation ended in 1968, Black representation in the medical profession could not recover from the Flexner Report. Today, Black physicians make up just 2.18 percent of the total physician workforce (Libby et al, 1997), far less than the representative 12.6 percent Black population (2010 U.S. Census). Undermining the Black medical profession further

exposed Black patients to exploitation that endangered their health as it made Black patients almost completely reliant on White physicians for their medical care.

D. Medical Experimentation on Blacks

Medical experimentation on Blacks, which started during the dominative paradigm, continued throughout, and beyond, the aversive paradigm, through government institutions and programs such as hospitals and prisons. Blacks under the control of White institutions such as hospital patients, and welfare recipients, were in power positions not very different from Black slaves under the control of their White masters. They existed under White perceptions of racial inferiority, information asymmetry, and the lack of other health care options. The proximity of city hospitals to Black housing locations and their dependence on welfare programs, made uneducated Blacks the primary teaching material for many hospitals. The following cases serve as a few examples of the consistent pattern of medical exploitation.

a. Testing for Radiation

Between 1944 and 1994 the Atomic Energy Commission (AEC), under the supervision of Robert Stone, conducted more than two thousand experimental projects utilizing radiation and human subjects studies in which Blacks were overrepresented. The majority of the experiments were conducted in the late 1940s as part of the Manhattan Project to test the effect of radiation on human subjects. One example was the case of Elmer Allen, A Black American who worked as a Pullman porter for a

California train company in San Francisco. After a work injury, which rendered Elmer unemployed and unemployable, he reluctantly went to the free clinic at the University of California, San Francisco. In 1947, Elmer was diagnosed with chondrosarcoma, a slow-growing and late-to-metastasize cancer of the bone. During his hospital stay, doctors injected Elmer with an extremely radioactive plutonium isotope. Elmer was falsely told that the injection was therapeutic and was a last ditch effort to save his leg. Three days later, Elmer's leg was amputated.

The experiment had a clear social cost for Elmer. He suspected that he had been the subject of a medical experiment and that the amputation was unnecessary. He began drinking and suffered epileptic seizures. Elmer's suspicions were correct. Cancer had nothing to do with the amputation. The doctors amputated his leg to study the plutonium effect on his tissues. Thirty years later, government scientists needed more tissue. They transported Elmer to The Center for Human Radiobiology to examine his bones and excreta. The scientists ascertained that Elmer still had lingering radiation in his body despite the fact that his leg was removed only three days after the injection.

By most accounts, Elmer was not the only Black American to be subjected to such an exploitive experiment. According to Robert Stone, in July 1947 twenty Americans were injected with plutonium. Fifteen of them were White and five were Black. Thus Blacks constituted 25% of the subjects at a time when they made up only 10% of the population. This means that their rate of involvement was two and a half times greater than it should be (Washington, 2006, 217-223).

b. The Tuskegee Study

All medical experiments on Blacks constituted violations to the patients' health. However, the Tuskegee experiment took medical experimentation to an unprecedented ethical low. Beginning in 1932, teams of government scientists conducted a long-term study on the effects of syphilis on poor Black men in Alabama. The study ran for more than forty years and was allowed to continue even after effective treatment became available.

The study represented unethical conduct for several reasons. First, the study had nothing to do with treatment. It did not test new drugs, nor did it test the efficacy of existing treatments. It was merely a non-therapeutic experiment aimed at compiling data on the evolution of syphilis. Second, the study did not add knowledge to the medical field because data on the disease evolution had already been compiled and published. A Norwegian review of medical records belonging to two thousand untreated syphilitic patients examined at an Oslo clinic was published in 1929, four years before the beginning of the Tuskegee study. Third, the experimental subjects, who would have benefited from the newly discovered Penicillin treatment in 1955, were never informed of the availability of the new drug. Instead, supervising physicians insisted on continuing the study with the idea of eventually bringing subjects to autopsy. Fourth, supervising physicians deliberately lied about the nature of the study by telling subjects they were actually getting treatment. Fifth, the sheer length of the study, lasting forty years instead of the original intended span of six months, was unjustified. Sixth, study subjects were never given information about the nature of syphilis as a sexually transmitted disease,

information that the men could have used to prevent syphilis transmission to their spouses (Jones, 1981).

The breakthrough report about the Tuskegee syphilis study in the national media in 1972 shocked the medical community and the general public. In response to mounting pressure, the Department of Health, Education, and Welfare appointed a panel to investigate the study. The investigation failed to provide justice to the Blacks American community for several reasons. Panel members were only allowed twelve meetings over a period of seven months to investigate the forty-year study. Upon realizing the magnitude of the mission, panel members requested an extension, but their request was denied. In addition, the scope of the investigation was narrowed to determine whether the study was justified and whether it should continue (Jones, 1981).

More importantly, the investigation did not address why researchers involved in the study withheld the drug arsphenamine, the standard treatment option before penicillin from patients. Nor did the investigation address the fact that that the researchers did not tell study subjects the truth about the nature of the disease and the study. Panel members realized that the government had no interest in revealing the truth about the. And finally, the panel investigation was sabotaged by the panel chair. The chair insisted on destroying the most important piece of evidence the panel collected, a tape containing interviews by all panel members with surviving study participants as well as the testimonies of medical staff members responsible for the study. The study chair even distanced himself from the final report and recommendation which the panel submitted to the Department of Health, Education, and Welfare (HEW)

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(later split into the Department of Health and Human Services and the Department of Education), even after he pressured panel members to water it down (Washington, 2006, 169).

The Department of Health, Education, and Welfare (HEW) handling of the investigation sent a clear message to the Blacks American community, that the lives of Black people were expendable regardless of the political climate. The fact that the study was allowed to continue throughout the Great Depression, the New Deal, and the Great society, passing through several Republican and Democratic administrations, means that anti-Black sentiment is deeply entrenched in the American psyche, transcending the different ideologies and social orientations.

E. Controlling the Black Population through Eugenics

The Eugenics movement, which prevailed in the early Twentieth Century, was another hallmark of the aversive paradigm. With wide financial and scientific support from capitalist institutions like Carnegie and Kellogg, and prominent universities like Harvard, MIT, and Columbia, the movement aimed to fulfill the policies of social Darwinism in order to improve the American genetic stock by eliminating those with inferior genetic characteristics. Hence, Mongolians, Jews, Gypsies, and American Indians were destined for extinction. Blacks were designated to the lowest rank of all human races. Therefore, they were targeted for the most aggressive eugenics practices (Washington, 2006).

Positive eugenics included banning any form of nurturing to those who were doomed to extinction due to their inferior genes. Nurturing, such as that provided by schools, vaccinations, equality of opportunity, hospitals, clinics, improved living and working conditions, and other assistance, was considered harmful to the society at large. First, it wasted taxpayers' money. Second, nurturing led to the perpetuation of inferior genes, increasing the risk of their dissemination among the White population.

Positive eugenics was implemented through Jim Crow laws, which provided the legal exclusion of Blacks through residential and medical segregation, and through economic isolation. Jim Crow laws were also implemented by banning interracial marriages. Inter-racial marriage between Whites and Blacks sparked concern among eugenicists. A textbook published in 1916 informed readers that "many students of heredity feel that there is a great hazard in the mongrelizing of distinctly unrelated races....only the most worthless and vicious of the white race will tend in any considerable way to mate with the negro race, and the result cannot but mean deterioration on the whole for either race" (Roberts, 1997, 71).

Negative eugenics, the more aggressive application of social Darwinism, included the active prevention of procreation by inferior races through birth control and involuntary sterilization. Though it did not enjoy the same legal cover as positive eugenics, negative eugenics was widely practiced in the first half of the Twentieth Century. The concentration of Blacks in public hospitals made them an easy target for unauthorized and involuntary sterilization (Byrd & Clayton, 2002, 68-74).

Negative eugenicists legitimized involuntary sterilization by reviving the slavery era practice of punishing slaves through castration. In Texas, Dr. Gideon Lincecum published an essay advocating the castration of a "vicious, disobedient, drunken Negro" criminal suspect as a deterrent to crime. The idea of sterilization as a solution for antisocial behavior was popularized in medical journals of the era. Between 1909 and 1910, medical journals published twenty three articles promoting sterilization as a solution to control antisocial behavior. In 1899, Dr. Harry Sharp, a physician at Indiana Reformatory, pioneered a plan to remedy race degeneration by sterilizing criminals. In 1902, he published a report about the beneficial results of the operations he performed. Over the course of ten years, Dr. Sharp performed vasectomies on 456 prison inmates (Roberts, 1997, 66).

The Eugenics Record Office (ERO), the largest and most influential eugenics research organization in the United States, was established in 1910 with funding from the Rockefeller and the Carnegie Foundations. The ERO published eugenics books and pamphlets for the general public and lobbied federal and state governments to pass sterilization laws (Cohen, 2016, 7). In 1914, the ERO proposed a schedule to sterilize 15 million people over the next two generations. They also provided a model of sterilization laws to accomplish this plan (Robert, 1997, 67).

Women bore the brunt of the eugenics movement. The White image of the Black race was especially denigrating to Black women in general and Black mothers in particular. Images of promiscuous, hyper-fertile, and negligent Black unwed mothers were popularized as a social menace in need of government intervention. Supposedly,

these women, through their unregulated reproduction, transmitted inferior mental and physical traits to the product of conception of their genes, and thus posed a threat to society's moral standing, social order, and financial resources (Robert, 1997, 12).

The theory of negative eugenics was of particular interest to Margaret Sanger, the famous birth control activist. In her book, *The Pivot of Civilization*, Sanger claimed that "eugenics is chiefly valuable in its negative aspects." She considered promoting access to birth control as the greatest step toward race betterment. With the support of eugenicists, Sanger established the 1938 "Negro Project," consisting of clinics in urban areas designed to provide poor Black women with free or cheap birth control pills (Washington, 2006, 196). Over the following decades, the Black community raised concerns about the motives of the Negro Project, which later became known as Planned Parenthood. In 1954, an article in *Ebony*, the Black magazine, urged Blacks to have large families as an insurance against Black extermination. Similarly, in 1973, a survey published in the American *Journal of Public Health* reported that nearly 40% of Blacks believed that programs like Planned Parenthood were a scheme to exterminate Blacks. The survey concluded that: "*The findings of the present study indicate that the genocidal fears are widely held in the Black population and that factors of age, sex, region and educational level are related to the prevalence of these fears*" (Tumer & Darity, 1973).

The birth control pill was not the only form of contraception used to incentivize birth control. In the 1990s, all states made Norplant available through Medicaid in spite of budget shortfalls. Norplant, an implant that releases hormones internally, differs from the pill in its relative permanence. Unlike the pill, a woman cannot simply stop using

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Norplant. She has to rely on a provider for removal. Women have experienced formidable difficulties in finding physicians willing to remove Norplant. This is particularly alarming considering the relatively higher bleeding and infection rate associated with Norplant in comparison to the pill. Moreover, poor women are not always provided with adequate information about Norplant's potential risks. A study of young, low-income women in South Carolina found that a majority of these women were given information that emphasized the benefits and minimized the possibility of adverse side effect (Roberts, 1997, 91-112).

Prevention of Black procreation did not stop with Norplant. Mounting evidence reveals that throughout the Twentieth Century, Black women have been disproportionately subjected to involuntary hysterectomies as a form of sterilization. In 1965, Fannie Lou Hamer of the Mississippi Freedom Democratic Party informed a Washington D.C audience that she, along with 60% of Black women in Sunflower County Hospital, Mississippi had been subjected to involuntary postpartum hysterectomy. The practice of sterilizing Black women by performing hysterectomies was so common in the South that these operations came to be known as "Mississippi Appendectomies."

However, this practice was not confined to Mississippi or to the South. A 1973 Los Angeles study found that doctors were subjecting poor Black women to surgical sterilization without explaining either the potential hazards or the alternative methods of birth control. In addition, in the 1970s, most teaching hospitals in New York had an unwritten policy to perform elective hysterectomies on poor Black women with minimum

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indications to train residents. The number of involuntary hysterectomies performed throughout the nation will never be known. Doctors routinely forged consent forms, or falsified medical records to reflect an appendectomy or gallbladder removal (Roberts, 1997, 90 & Washington, 2006, 202).

3. Systemic Racism Paradigm

As Kovel (1970) notes, racism cannot be legislated away. It simply transforms to accommodate new realities. Racist ideology reacted to Civil Rights Era legislations that Benefited Black Americans by adopting an ostensibly objective and even moral arguments that perpetuated White domination. During the early Twentieth Century era, Whites looked to government to legislate, codify, and enforce segregation. In contrast, under the new paradigm, White racism called for limiting the role of government of enforcing black integration and allowing Blacks to achieve equal status. Different writers identified the new paradigm of racism in different terms. Kovel (1970), for instance, refers to it as meta-racism because it has assumed characteristics from the two previous forms of racism, but in a calm, and seemingly objective way. Eduardo Bonilla Silva, on the other hand, refers to it as color-blind racism because it rationalizes the current status of Blacks as a product of neutral market forces (Bonilla-Silva, 2006, 7). The term systemic racism denotes the structural barriers Black-Americans encounter when dealing with American society and institutions. This racism hinders their full and equal participation in all facets of life, including education, employment, and civic activity.

Systemic racism frame is based on classical liberalism. White racism revived classical seventeenth-century liberalism, which emerged as a response to autocratic monarchies. Post-Civil-Rights Era liberals, who became known as neo-liberals, used similar logic in arguing against government intrusion on individual liberties spawned by forced integration and affirmative action. They emphasized individual freedom and contended that force should not be used to achieve social policy. White neo-liberals believed that individual choice, unhindered by government intrusion, encouraged hard work, high productivity and innovation, whereas a system where government enforced social policy incentives lowered productivity and resulted in laziness. This argument ignores the past and persistent effects of discrimination on the economic and educational status of minorities and taints the policies of equal opportunity as unfair. It effectively uses the "blame the victim" strategy by placing the blame on Blacks for the lag in their achievement (Bonilla-Silva, 2006, 4).

Minimization of the problems associated with racism is another form of post-Civil Rights Era racism. The notion that segregation is no longer legal or acceptable allows Whites to dismiss the need for laws to ameliorate past effects of racism. Thus, social programs that benefit Blacks are deemed unjustified. This argument builds on the previous argument that current non-segregation policies provide equal opportunities to all Americans. Falling behind in educational and economic achievement is posited as an individual failure rather than a societal responsibility (Bonilla-Silva, 2006, 26).

The election of Ronald Reagan in 1980 marked the official onset of the systemic racism paradigm. Reagan championed the current neo-liberal political and economic

structure with his resolve to minimize the role of the federal government by transferring power back to the states, and to maximize the role of the free market. The result was an array of neo-liberal social policies that reduced subsidized housing, healthcare, and welfare benefits for the poor. The neo-liberal policies relating to Blacks are predicated on three interrelated presumptions. The first assumption is that the Civil Rights movement was successful in achieving its goals in eliminating racism, which means that Blacks have equal access to all the social and economic benefits they need to prosper, which include equal access to high quality education, employment, housing and health care. The second assumption is that racism is no longer a factor contributing to the unequal economic status of Black in comparison to Whites. The implication of this assumption is that Blacks' lower socioeconomic status is the product of their own underachievement. The third assumption is that the elimination of discrimination means that Blacks have ample opportunity to achieve upward mobility within the current non-discriminatory economic structure. This assumption shifts the blame on Blacks for their lagging upward achievement (Bonilla-Silva, 2006, 25).

For Reagan and the neo-liberals, values such as efficiency, hard work, and self-reliance were the overarching goals according to which they designed their policies. They completely dismissed the results of the Blacks American historic experience with racism and its enduring consequences. Indeed, decades of economic and social segregation has left Black Americans with lower levels of education and lower employment rates than Whites. Consequently, Black Americans had an overall lower socioeconomic status and worse working and living conditions than White Americans as

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well as reduced access to health care coverage (Grant, 2008). Blacks are also more reliant on the White medical profession thanks to changes in medical school polices that reduced their access to medical education

A. White Medical Profession

White physicians' persistent pattern of prejudice towards people of color is discussed in John Hoberman's book, *Black and Blue: The Origin and Consequences of Medical Racism* (2011). According to Hoberman, many White physicians share the classical liberal views with their fellow citizens that oppose the idea of federal government intervening in people's lives. Their application of this ideology translates to the belief that government should not intervene to improve Blacks' living standards as a compensation for past racism (Hoberman, 2011,12). In addition, the encounters medical doctors have with their Black patients reinforce Black stereotypes. These encounters begin in urban teaching hospitals where medical students and residents get their clinical training. Black patients, who often live in nearby poor, inner-city neighborhoods, and rely on emergency room services for their health care needs, provide the clinical teaching material to these rising professionals.

This White-doctor-and-Black-patient setting provides a perfect breeding ground for racism for even the most well-intentioned doctors. Black patients show up in the emergency room for a wide variety of seemingly self-inflicted problems ranging from gunshot wounds from gang violence to drug and alcohol related health problems to domestic violence. Even benign emergency cases typically involve diseases that could

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have, and should have been prevented. These diseases range from diabetes and heart conditions to various types of cancer cases. White physicians-in-training perceive that African American patients intentionally neglect these conditions for long periods of time and only show up in the emergency department when their ailments reach a dangerous phase (Hoberman, 2011, 21). By the end of their training years, the perception of violent, undisciplined, and less intelligent Black patients are well entrenched in the psyche of many White physicians, particularly those who received their training in inner city hospitals.

Hoberman argues that the lower rate of treatment of Black patients is not only the result of fear of doctors. It is also the result of racial differential diagnoses and treatment by physicians. As an illustration, Hoberman compares the management in cases where surgery is beneficial to the patient cases where non-surgical treatment is preferable. Heart surgeries are generally regarded as beneficial, yet Black patients undergo these surgeries less often than White patients. Conversely, Black patients with diabetes and circulatory problems were less likely than Whites to have leg-sparing surgery and more likely to have their legs amputated, according to a 1998 study (Hoberman, 2011, 35). Such differential management cases illustrate White disrespect for the Black body and reaffirm the suspicion Blacks have of White medicine.

Vanessa Gamble makes a similar observation about the differential diagnoses of White physicians on the health conditions of Black patients. She uses the example of Alicia Georges, a professor of nursing at Lehman College and former president of the Black Nursing Association. When Georges presented herself at a hospital emergency

department with acute abdominal pain, the department staff presumed that pain was due to pelvic inflammatory pain spurred on by excessive sexual activity, thereby labeling her as a "typically" promiscuous African American woman (Gamble, 1997).

B. Undermining the Black Medical Profession

One way to improve care for Black patients is to provide them with medical care at the hands of Black physicians. LaVeist, et al. examined a national sample of Black, White, and Hispanic respondents about the hypothesis that doctor-patient race concordance is predictive of patient satisfaction. The study found that among each race/ethnic group, respondents who were race concordant reported greater satisfaction and higher rates of utilization with their physicians compared with respondents who were not race concordant (LaVeist, et al., 2003). Thus, to increase the African-American patient satisfaction rate, the number of Black physicians needs to be increased from the current 2 percent rate to a more representative 12 percent, the current African-American population rate.

This task was well under way in the 1960s after the integration of medical schools and the enactment of Affirmative Action. However, this pattern of expansion began to be reversed with the onset the systemic racism paradigm. The 1977 U.S. Supreme Court case *Regents of the University of California v. Bakke* exemplified how this new type of racism played out. The Court ruled against using race as an admission criterion to the University of California Medical School. This rule, which conforms to the general White public sentiment against Affirmative Action and equal protection laws, was followed by

more challenges to government intervention for social change, including the 1997 Fifth District Court of Appeals in *Harpwood v. Texas*, and the California Civil Rights Initiative, Proposition 209 banning the use of race and gender criteria in higher education admission decisions. Consequently, medical schools throughout the nation are seeing decreased Black student admissions. In 1997, Texas public medical schools witnessed a 54% decrease in Black student enrollment. Similarly, the number of Black medical students in California decreased by 32 percent in 1998 (Smedley et al., 2003, 122). Student enrollment rates have also decreased in other states that banned affirmative action, such as California, Florida, Michigan, and Washington (Fessenden & Keller, 2015).

The implication of this trend is that the health care of Black patients will continue to be dominated by White physicians, leaving these patients with a lower quality and quantity of care. Black patients are four times more likely to receive health care from White rather than from Black physicians. Prevailing White stereotypes of Black patients will continue to have a negative effect on the quality of care those patients receive. In addition, Black physicians are more likely to practice in Black, medically underserved communities. A study of physician practices in California found that over half (52 percent) patients of Black physicians are Black, compared to only 9 percent among White physicians' practices (Smedley et al., 2003, 122). A dwindling supply of Black American physicians will leave African American patients ever more vulnerable to White medical racism. In addition, Blacks' lower socioeconomic status creates structural and cultural barriers that reduces their ability to access to health care services in comparison

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to Whites (Betancourt et al 2003).

C. Structural Barriers

Structural barriers are those rooted in the social and economic systems that disadvantage Black Americans. They stem from the neo-liberal social and economic policies that limit government role and expand the role of free markets. With respect to the health care system, structural barriers stem from a lack of adequate insurance coverage, and a lack of consistent sources of care (Cornelius & Altman, 1996).

a. Lack of Health Coverage

Historically, health insurance in the United States has been closely tied to employment. In 1980, up to 84% of working Americans received employment-based health insurance (Morone 2008, 211). By 2011, this ratio has dropped to 63% with the erosion of the industrial sector and rise of the service sector. Service sector jobs tend to be low-paying jobs and do not provide health insurance as a benefit. Black Americans are more likely to be employed in such low-wage service jobs (Luhby, 2014). Furthermore, the Black American unemployment rate has persistently remained double the unemployment rate of Whites (Bureau of Labor Statistics, 2016) even during the economic booms of the eighties and nineties. Higher unemployment rates leave Blacs Americans with less access to employment-based health insurance. These employment barriers lead to overrepresentation of Black Americans among the uninsured population. Black Americans make up 16 percent of the uninsured, a higher percentage than the overall 13 percent of uninsured of the general population (Barr, 2011, 258).

One implication of the disparities in health coverage is the lower rate of access to routine health care. Research shows a significant gap in access to health care between Black and White Americans. After controlling for possible explanatory variables such as gender and education levels, lower socioeconomic status among Black Americans was irrefutably a significant factor in the access to health care gap (Mayberry et al, 2000). Restricted access to health care is associated with low levels of health care continuity (Forrest & Starfield, 1998), which lead to reduced health quality and an increase of negative outcomes (Mainous, et al., 2001).

Black Americans face barriers to health care even when they do have insurance. Both private and public insurance arrangements create barriers that hinder Blacks American patients from seeking needed care. The structure of for-profit Managed Care Organizations (MCOs) and the administrative procedures of Medicare and Medicaid present obstacles for poor and sick individuals in general. Such obstacles disproportionately affect Black American patients since they tend to be over-represented among the poor and the sick.

b. For Profit MCOs

The concept of insurance emerged as a social arrangement operating in accordance with the solidarity principle. Under the solidarity principle, individuals contribute to health insurance according to their ability to pay but receive health care services according to their needs. The result of the solidarity principle is a social insurance in which healthy individuals contribute money into an insurance fund, which

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they may never use. In contrast, sick individuals may consume more money from the insurance fund than they contribute (Morone et al, 2008, 31).

Managed Care Organizations (MCOs), which gained influence with the election of Ronald Reagan and the economic liberalization that followed, operated according to a different principle called actuarial fairness. Under actuarial fairness, individuals contribute money to the insurance fund according to the quality of their risk. Thus, individuals with a family history of disease pay higher premiums than individuals with no adverse history. Further, sick individuals who seek health care services more frequently than healthy individuals have higher co-pays (Morone et al, 2008, 32). This insurance arrangement translates into higher out-of-pocket expenses and a heavier financial burden on Black Americans (Stone, 2005, 75).

Moreover, Managed Care Organizations (MCOs) maximize their efficiency and effectiveness by relying on utilization review and practice guidelines that ensure medical necessity of provided medical services. There are a number of different forms of utilization review, but they all rely on statistical norms, such as incidence of cancer and average life expectancy; and practice parameters, such as screening and preventive care, to decide whether a service is necessary. The problem with utilization review is that standards and decisions are made from data drawn from a largely White, middle-class, suburban dwelling group. For several reasons, such data are unreliable and inadequate when applied to the underserved Blacks American population (Randall, 1994, Rooks et al, 2008). For example, privately insured Blacks American patients with asthma have persistently shorter asthma-related hospital stays compared to White

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Asthma patients and were persistently discharged with unmet medical needs. This is particularly concerning given the fact that Black Americans have a higher incidence rate and greater morbidity, such as extreme fatigue, of asthma than White Americans (Brandt & St. Marie, 2011).

Underserved Black Americans typically enter into MCO contracts with a backlog of pre-existing conditions that have gone untreated. Since their illnesses are more severe and have more co-morbidities, they require more intense treatment over longer periods of time. As a result, the course of the treatment falls outside what MCOs consider a normal course. For example, Blacks with cardio vascular disease are more likely to enter MCO contracts with an existing hypertension condition and other co morbidities. They have worse outcomes than White patients with cardiovascular disease because of their other co morbidities (Randall, 1994, Rooks, et al, 2008).

Meanwhile, many Black American providers, who typically provide for the underserved Blacks American population, are excluded from MCO plans. MCOs refrain from including such providers with their plans to avoid the heavy utilization of medical services Blacks American providers recommend to their underserved sick patient population (Stone, 2005, 79).

c. Public Insurance

The public perception of enrollees in the publicly funded Medicaid program also creates barriers for Black Americans seeking needed medical care. Firstly, the manner in which states administer their Medicaid stigmatizes families who enroll in Medicaid

programs. The stigma is fostered by negative interactions with caseworkers and by long waiting times Individuals and families eligible for Medicaid fear being perceived as lacking personal responsibility and willingness to work toward achieving self-reliance, two deeply held values among the American public. This perception deters many eligible individuals from participating in the program (Stuber and Schlesinger, 2006). The stigma falls disproportionately on Black American patients because of their overrepresentation in the Medicaid program. Medicaid covers over twice as many Black Americans (27%) as Whites (12%) (Rowland, 2009).

d. Lack of Consistent Source of Care

Another problem with Medicaid is its provider reimbursement rates. Medicaid is well known for its notoriously low payment rates for physicians, nursing homes, home health agencies, hospitals, and other health care providers. For example, Medicaid reimburses physicians 29 percent, 38 percent, and 44 percent of private insurers rates in New York, California, and Florida, respectively (Roy, 2012). As a result, many physicians refuse to accept Medicaid patients. On average, only 64.7 percent of primary care physicians accept new Medicaid patients, well below the 81 percent acceptance rate for privately insured patients (Toland, 2012).

The choice of providers for Medicaid patients became even more restricted when various states moved toward MCOs in the late 1990s. Since 1997, states have required Medicaid beneficiaries to enroll in an MCO or a similar arrangement as a condition for coverage. Medicaid managed care beneficiaries have to find physicians who are willing

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to accept Medicaid patients and are contracted with Medicaid managed care plans. Finding such physicians is no easy feat. Thus, the Medicaid beneficiaries' options of providers is often limited to public hospitals and state-run health departments (Smedley et al, 2003, 679).

The move to managed care has another potentially damaging effect for Medicaid beneficiaries in general and Blacks American beneficiaries in particular. The Managed Care utilization review process and gatekeeping requirements are likely to be the reason behind the lower satisfaction rates which beneficiaries report. A 2001 study on racial and ethnic differences with regards to access to medical care in managed care plans found that Black Americans had a lower (less than 74 percent) access to primary care providers than White Americans (more than 78 percent). (Hargraves et al, 2001).

Medicaid managed care difficulties have a disproportionate adverse impact on Black Americans who are enrolled in Medicaid and Medicaid managed care plans because Black Americans are disproportionately represented the elderly poor who use Medicaid to supplement their Medicare coverage. The refusal by physicians and other providers to participate in Medicaid and Medicaid managed care plans forces Black American beneficiaries with such plans to choose between either forgoing treatment or paying their uncovered cost-sharing expenses out of pocket. For most low-income beneficiaries, the latter option constitutes a financial burden they cannot bear (Smedley et al, 2003, 683).

D. Cultural Barriers

Cultural barriers emanate from the set of distinct cultural attitudes and health beliefs that pose as barriers to cancer treatment. Black Americans share such set of beliefs about cancer because of their shared experience with racism and their memories of loved ones who died from it. Cancer treatment entails multiple visits to treatment facilities over a prolonged period of time, extending up to ten weeks for each treatment cycle. A treatment cycle is the period during which a cancer patient receives specified doses of radiation therapy, chemotherapy, or both, to kill cancer cells in a particular body organ. Additional cycles may be needed if the disease is not resolved, or if it returns. Treatment also entails constant monitoring of body organs to make sure they are cancer-free and to minimize potential negative side effects to cancer treatments (American Cancer Society, 2012). The long and painful process to recovery from cancer, along with probability of recurrence amplifies Black Americans' cultural attitudes towards cancer treatment. Literature cites fatalism, mistrust of physician, low levels of social support and self-efficacy as barriers to cancer treatment.

a. Fatalism

Fatalism refers to the generalized belief that outcomes are predetermined and cannot be changed. It is a cognitive orientation that diminishes the agency of the individual by placing the locus of control in an exterior factor, such as God or luck, leading individuals to believe that they have no control over their destiny. In the context of health, this orientation translates to a belief that illness is unavoidable and

untreatable. A diagnosis of a serious and chronic disease, such as cancer, exacerbates the sense of fatalism creating a conviction of death sentence due to the disease, hence cancer fatalism (Powe & Finnie, 2003, Franklin et al, 2008).

Cancer fatalism is more prevalent among Black American cancer patients. Because poverty amongst Black Americans results in focusing on daily activities rather than long-term health, they often overlook basic cancer screenings. By the time symptoms become present, the cancer would have progressed in such ways that limit treatment options and decrease survival chances. Decreased survival reinforces fatalistic perceptions about cancer and perpetuates the belief that cancer screening does not reduce the chance of getting and dying of cancer (Powe & Finnie, 2003).

Several studies have identified cancer fatalism as a barrier to cancer screening. For example, cancer fatalism is a major factor in preventing Black American men from seeking prostate cancer screening (Blocker, 2003), preventing both men and women from seeking colorectal cancer screening (Berry et al, 2009), and from seeking treatment of lung cancer (Franklin et al, 2008).

Fatalism prevents Black women from obtaining gynecological cancer screening (Dettenborn, 2005), and breast cancer screening (Peek et al, 2008). The degree of fatalism is usually higher among older and among individuals with lower education levels (Powe & Finnie, 2003).

b. Physician Mistrust

Black Americans' mistrust of physicians stems from the long history of exploitation

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of Black patients. Since their arrival on American Soil, Black slaves have endured cruel medical practices ranging from neglect and denial of basic medical needs to experimentation of new procedures and chemical compounds. These practices continued after emancipation and throughout most of the twentieth century (Byrd & Clayton, 2000, 264-317).

Slavery era medical schools opened public and slave hospitals and invited slave owners to send their sick slaves to their facilities to be treated and experimented on by medical students with no charge. The schools used Black slaves as training material to develop surgical techniques and test new drug compounds. Many of the surgical procedures performed today, such as cataract removals and hysterectomies are the product of White physicians' experimentation on Black slaves (Savitt, 2007, 86).

Exploitation of Black continued after emancipation and for most of the twentieth century. Black men and women were often subjected to involuntary sterilization during the eugenics movement in the early decades of the century. Until the 1970s, physicians in training hospitals routinely performed postpartum hysterectomies on poor Black women as a method to train medical students and surgical residents (Washington, 2006, 203).

For Black Americans, the Tuskegee medical experiment is the epitome of medical exploitation. For four decades, the study examined how syphilis kills its victims. To conduct the study, doctors withheld information about the disease from Black American syphilis patients, withheld treatment, and examined the progression of the disease until the patients' death. The study did not add knowledge about the disease, nor did it make

any effort to test treatment efficacy (Jones, 1981). The experiment has become part of the folklore of racism for Black people as generations passed down the story in their oral traditions creating a deep distrust in the medical profession and the health care system (Brandon et al, 2005).

With this deep history of deep mistrust, Black Americans are less likely than Whites to trust their doctors and follow their recommendation, and less likely to agree that their doctor would fully explain medical research (Boulware et al, 2003; Armstrong et al, 2007; Musa et al, 2009). Many Black Americans still perceive discrimination in differential diagnoses and treatment (Blocker et al 2006). The perception of discrimination persists even in the absence of real discrimination, and it is more prevalent among older Black Americans who had earlier experiences with discrimination (Hammond, 2010). Other factors, such as socioeconomic status, gender, and personal experience with racism affect trust levels. For example, Black men are less likely to follow their doctors' recommendation and have the PSA test for Prostate cancer than White men (60.1 percent to 72.1 percent), while Black women are twice as likely as White women to follow the doctors' recommendation with mammograms (Musa et al, 2009; Hammond, 2010).

c. Low Levels of Social Support

The Black American culture stigmatizes cancer diagnosis as a source of shame. The stigma stems from a variety of myths about cancer. Some Black Americans think that cancer is a contagious disease and that the stricken should be avoided; others

believe that cancer results from a genetic flaw; yet others believe that a cancer diagnosis is a punishment for not living according to God's will. These myths about cancer make it difficult for Black American cancer patients to talk openly about their diagnoses and seek cancer treatment (Im, 2008).

Inability to discuss cancer deprives Black cancer patients from seeking and obtaining social support. Belgrave & Lewis (1994) indicate that adherence to treatment increases among Black Americans with chronic diseases as the level of social support they receive increases. Social support includes emotional, material, and cognitive support. Emotional support refers to behavior that fosters feelings of comfort and leads an individual to believe that he or she is admired and respected, and that others are available to provide caring and security. Providing a patient with reassurance and comfort is a form of emotional support. Material support refers to goods and services that help solving practical problem. Providing transportation to the treatment facility is an example of material support. Cognitive support means providing information, knowledge and advice, such as tips on taking cancer medication or coping with radiation treatment (Jacobson, 1986).

d. Low Self-Efficacy

Self-efficacy is an individual's own perceived ability to perform a specified behavior, or set of behaviors (Anderson et al, 2006). For cancer patients, self-efficacy directly affects patients' ability to effectively communicate with health care professionals and maintain a positive attitude, both of which affect the quality of treatment decision-

making and adherence to clinical recommendations and treatment regimen. Low self-efficacy negatively influences Black men's adherence to cancer screening and early detection activities (Wolf et. al., 2004).

Notably, Black American patients have equal levels of self-efficacy compared to White and Hispanic American patients for diabetes self-management. They also have higher levels of self-efficacy in treatment for alcohol and cocaine use than White and Hispanic patients (Warren et al, 2007).

V. Conclusion

Racism against Black Americans followed different patterns throughout the American history depending on the different social and political settings. It manifested in exploitation of the Black slaves during the dominative paradigm, segregation and exclusion during the aversive paradigm, and a lack of corrective measures as well as a continuation of some elements of exploitation and exclusions under the systemic racism paradigm.

Regardless of the differences between the paradigms or racism, they all brought the same wretched health disparities to Black Americans. Cancer disparities are a prime example of such disparities, as cancer constitutes the second leading cause of death for Black Americans after heart disease. Black Americans have a higher cancer incidence and higher cancer death rates than their White compatriots. The Healthy People Programs, under the auspices of the Center of Disease Control and Prevention has been striving to minimize cancer disparities between Black and White Americans since

the 1990s.

Because of the persistent racism, Black Americans face structural and cultural barriers that reduce their access to adequate and timely cancer care. Structural barriers emanate from the expansion of for–profit Managed Care Organizations, and from scaling back public health insurance programs, such as Medicaid, both of which disadvantage the poorer Black American population. Cultural barriers stem from the convictions and attitudes that some Black Americans have developed over the years in relation to health, disease, and the medical profession.

Reducing cancer disparities among Black Americans requires mitigating both structural and cultural barriers. Reducing structural barriers entails increasing Black Americans' access to cancer preventive and treatment services through affordable insurance polices with a wide network of physicians and treatment facilities. Reducing cultural barriers entails finding elements in the Black American culture that promote healing by reversing fatalism, physician mistrust, low social support and low self efficacy.

Chapter Two

Towards Closing Cancer Disparities

I. Introduction

Expansion of the health care system in the twentieth century provided easier access to health care services for most Americans. The two major expansions occurred with the 1946 Hill Burton Act and the 1965 Civil Rights Movement. Black Americans' benefit from the Hill Burton Act was only marginal because the Act cemented segregation in the health care system and excluded Blacks from advances in the medical field which White Americans enjoyed. In contrast, the expansion associated with Civil Rights Movement greatly improved Black Americans' overall health. However, cancer incidence and mortality rates continue to be higher among Black than White Americans even after Civil Rights Era medical benefits expansions. Corrective programs to mitigate cancer disparities began in the 1990s following reports from the Department of Health and Human Services and the American Cancer Society that highlighted some underlying causes of cancer disparities. The programs, which focused on structural barriers to cancer care, have succeeded in improving screening, diagnosing, and staging, but not treatment rates.

Black Americans' experience with racism has shaped their cultural attitudes towards cancer diagnosis and treatment. They became mistrustful of the White

dominated medical profession, and have turned to religion to alleviate their suffering when afflicted with cancer. As devout Christians, many Black Americans strongly believe in healing through faith and prayer as well as involvement in church. Faith and church involvement has improved the health and lives of Black Americans throughout history, and continue to do so at the time of the present research.

II. Expanding Access to Health Care to Black Americans

The first half of the twentieth century witnessed intense debates about the nature of a health care system that an increasing number of Americans were demanding. Labor organizations pushed for a national health insurance system while the insurance and hospital industries, along with the medical profession lobbied heavily to keep health care services in the private sector. The debate yielded the Hill Burton Act of 1946. The Act was a modest step towards closing the health care quality racial gap. The 1946 law authorized a five-year, $75 million grant in-aid to states for the purpose of constructing a modern hospital system and a grid of public health centers to meet population needs according to the geographic and racial distribution. To qualify, each state had to assess its hospital needs and agrees to match federal funds on a two-to-one basis. States also had to supervise hospital projects to ensure compliance with the law. The Act contained a non-discrimination clause requiring hospitals to admit patients regardless of creed, color, or ethnicity (Morone et al 2008, 13).

Southern states were the major beneficiaries of the Hill-Burton Act. For many Blacks in the rural south, the Act allowed access to new hospitals wards, a novelty

which they'd never before had. These states built segregated wards on a generous scale. The typical beneficiary hospital was a small facility with approximately 50 beds, operating in a community of fewer than 5,000 residents. However, medical historian Dr. Montague Cobb contended that the Act cemented segregation because it allowed hospitals to construct segregated wards for Blacks, even though those wards provided care equal in quality to White wards (Beardsley, 1987, 179).

The Hill-Burton Act was less beneficial to the Black medical profession and poor Black patients. Although the Act allowed Black physicians to follow their private patients to the hospital, it did not permit the recruitment of Black residents and interns. The Black medical community feared that such exclusion would eventually deprive southern Black patients of an adequate supply of Black physicians since the physician supply would not be replenished as older physicians retired. Finally, the Act did not benefit poor Blacks since it prevented Black doctors from treating charity patients (Beardsley, 1987, 179).

Unsatisfied with the Hill-Burton Act, Black Americans began pushing for further health care expansion through a medical Rights movement, which paralleled the Civil Rights movement. Their efforts culminated in the enactment of Medicare as an expansion of the 1935 Social Security program (Morone, 2008, 332). Most Black Americans did not initially benefit from Social Security or Medicare since their average life expectancy was less than 65 years (National Bipartisan Commission on the Future of Medicare). However, they did benefit from two minor add-on components to the Medicare Act: Medicaid and the Neighborhood Health Center Programs.

Medicaid was created through the 1960 Kerr-Mills Act, which provided generous, open-ended federal matching funds for all venders (providers such as hospitals and nursing homes) with payments on behalf of low-income elderly. Medicaid expanded Kerr-Mills coverage for families with dependent children who had been certified by their respective states as medically indigent. Legislators who approved the Kerr-Mills Act perceived Medicaid as a minor piece of the Medicare legislation that would have only a minimum impact on the federal budget. The program allowed states to determine eligibility requirements and vendor reimbursement levels (Marone et al, 2008, 334).

President Lyndon B. Johnson established the Center for Economic Opportunity (CEO) in 1974 as part of his effort to eliminate poverty among Americans. The CEO provided grants for medical schools, hospitals, health departments, and community groups to plan and administer neighborhood clinics to provide primary and preventive care to low-income individuals with no health coverage (Sardell, 1988, 51). Blacks, who were disproportionately represented in the low-income socio-economic strata, were major beneficiaries of the two programs. Increased access to health care services made possible by Medicaid and Neighborhood Health Center programs resulted in improved Black health outcomes. Studies show lower mortality rates for both infants (34.2 to 24.5 per thousand) (Chabot, 1971), and an increase of life expectancy for adults (8 years) (Hummer, 1996), with most improvements accomplished in the poorer southern regions due to higher funding (Almond et al., 2003). However, the gap between Black and White health outcomes leveled off after 1975 and began to rise as the systemic racism paradigm commenced.

III. **Persistent Cancer Disparities**

The social and economic policies that marked the end of the aversive paradigm improved the overall health of Black Americans. For example, The *Brown vs. Board of Education* case and Title VII of the Civil Rights Act provided Black Americans with better education and employment prospects. Title VIII of the Civil Rights Act provided them with equal housing opportunities. Title VI of the Act gave Black Americans access to medical services through the Medicare, Medicaid, and community health programs. Together, these policies translated to better living conditions and more job security. They meant less stress associated with financial security and higher self-esteem. The overall effect of these policies was improved Black Americans' Health outcomes. Life expectancy at age 35 increased by an average of 2.5 years for Black women, and 0.5 for men (Kaplan et al, 2008).

Despite these improvements, however, Black Americans continue to have higher cancer incidence and mortality rates than White Americans. The United States' Department of Health and Human Services was the first to shine the light on cancer disparities among Black Americans in its 1985 "*Report of the Secretary's Task Force on Black and Minority Health*", known as the *Malone Heckler Report.* The report attributed cancer disparities to lower socio economic status and higher rates of tobacco and alcohol consumption among Black than among White Americans (Report of the Task Force on Minority Health, 1985, 87). The Report inspired the American Cancer Society to conduct its own study on Cancer among Black Americans. The Society's study uncovered three types of barriers that lead to higher cancer incidence and

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mortality rates among Black Americans: financial barriers relating to lack of insurance and inability to pay for screening and treatment expenses; logistical barriers dealing with the inability to navigate the health care system and coordinate care among providers; and cultural barriers dealing with perceptions about the health care system and cancer (Cancer. Org; Freeman & Rodriguez, 2011). This dissertation focuses on the latter type of barriers.

IV. Corrective Programs to the Rescue

In 1990, Dr. Harold P. Freeman launched a program at a Harlem Hospital in New York City to improve cancer outcomes for minority women with breast cancer. He recruited two groups of breast cancer patients, mostly Black American women. The first groups consisted of 325 navigated patients, and a control group consisted of 281 non-navigated patients. Navigated patients received assistance in early diagnosis, timely treatment, and follow up care, whereas non-navigated patients did not. The program reduced navigated patients' cancer stages and improved their survivor rates in comparison to the non-navigated patients. Of the 325 navigated patients, 41 percent were navigated at stage 0 and 1 cancer, and 21 percent were navigated stage 3 and 4 cancer. The 5-year survival rate was 70 percent. In contrast, the non-navigated group had only 6 percent stage 1, and 49 percent stage 3 and 4. The 5-year survival rate was only 39 percent (Freeman & Rodriguez, 2011).

These impressive results spawned national interest in the patient navigation approach. In 2005, the federal government provided grants to hire and train patient

navigators to assist minority cancer patients with obtaining timely cancer diagnosis, treatment, and follow up. In addition, the Center of Medicare and Medicaid, in collaboration with the Health Resource and Administration (HSRA), authorized six demonstration projects for a variety of chronic conditions, including cancer. In 2010, HSRA added ten navigation demonstration projects (Paskett et al, 2011).

Improving adherence to cancer treatment and closing the racial gap in cancer rates was also part of the *Healthy People 2020* project that aimed at eliminating racial and ethnic disparities in infant mortality, diabetes, cancer screening and management, heart disease, AIDS, and immunization (Harper & Lynch, n d). To that end, a few cancer centers established Patient Navigation Programs (PNPs), through public and private funding, to close the gaps in cancer incidence and mortality rates between Black and White Americans.

V. Successes and Failures of Patient Navigation Programs

Patient Navigation programs promote timely intervention throughout the cancer care continuum for racial and ethnic minorities. The continuum begins with screening and diagnosis; followed by treatment, rehabilitation and continuous follow up until the patient's end of life. Therefore, success of navigation programs hinges on their ability promote timely intervention by eliminating all barriers that face minority patients throughout the cancer care continuum. Navigation programs have succeeded in increasing rates of screening, early diagnoses and staging. However, they have not increased rates of treatment. Moreover, none of the patient navigation programs offer

rehabilitation and follow up (Freedman & Rodriguez, 2011).

1. *Screening*

Navigation screening services include assisting patients with setting appointments, filling out insurance paperwork, arranging for transportation, coaching patients on effective communication with providers, and coordinating medical care**.** Most of the studies on PNPs' efficacy investigated the programs' success in increasing screening for colorectal, cervical, and breast cancers. The majority of study groups were Latinos, Native Americans, Chinese, and Black American minorities. According to these studies, PNPs have successfully increased low-income minority population participation in screening for colorectal cancer by 27 percent (Jandrof et al 2005), breast cancer by 29 percent (Clark et al, 2009), and cervical cancer by 18 percent (Wang, et al, 2010). These results suggest that patient navigation impacts cancer patients in a favorable manner because participants in these studies who received navigation services were significantly more likely to complete cancer screening than those who did not (Paskett, et al 2011).

2*. Diagnostic Follow-Up*

Only two studies investigated the impact of patient navigation on diagnostic follow-up. The first one compared 196 low-income Latina women, who enrolled in a navigation program, to a control group of 369 non-enrollees. Members of the two groups had a suspicious cervical lesion requiring a diagnostic follow-up. Adherence rate among the

navigated group was 67 percent compared to only 32 percent among the non-navigated group (Ell et al, 2004).

The second study involved 1018 navigated and 314 non-navigated inner-city women of diverse racial and ethnic backgrounds with breast abnormalities that required follow-up. Navigated women were 39 percent more likely to have a timely follow-up than the non-navigated women (Battaglia et al, 2006). The two studies indicate that patient navigation programs positively impact diagnostic follow-up.

3. *Staging*

Delayed staging contributes to cancer disparities. Black Americans are typically diagnosed with more advanced stages of cancer, which limits their treatment options and reduces their chances of survivor. Navigation staging has achieved a modest success in early cancer diagnosis. A study on underserved populations comparing a cohort of navigated breast cancer patients to a control cohort treated before the initiation of navigation program found a 22.8 percent reduction in cancer stages 3 and 4, among the navigated women, and a 20.3 percent increase in stages 1 and 2 compared to non-navigated women. The study also noted an increase in Medicaid participation among the navigated women. The increase in Medicaid participation was attributed to navigators' assistance in the Medicaid application (Haiden & Moormeier 2011). Navigation improves staging for Black American women in particular. A study on 487 breast Black American cancer patients, concluded that navigation services increased early breast cancer staging (stage 0) by 12 percent, and decreased invasive cancer

staging (stage 4) by 7 percent (Gabram et al, 2008).

While screening, follow-up diagnosis, and staging are important steps in combating cancer disparities; they have little impact in reducing cancer mortality rate if they do not lead to treatment. Unfortunately, disparities in cancer outcomes persist even with PNPs' efforts in achieving earlier diagnose and staging (Hendren et al 2011). Navigation treatment programs have not achieved the same levels of success in increasing treatment rates as screening, staging, and diagnostic follow up programs have despite improving treatment continuity and patient satisfaction rates.

4. *Treatment*

Cancer treatment is an important step towards closing cancer disparities, a major objective of Healthy People 2020 goal. Treatment navigation began in 2008 in only five of the ten facilities that participate in PNPs (Paskett et al, 2011). Cancer treatment differs from screening and staging in that it requires continuity of care through multiple visits to treatment facilities over a prolonged period of time, extending up to ten weeks for each treatment cycle. Additional cycles may be needed if disease remains present, or if it returns. Treatment also entails constantly monitoring and testing body organs to make sure they are cancer-free, and to minimize potential negative side effects to cancer treatments (American Cancer Society, 2014).

A few studies revealed PNPs' success in improving patients' continuity of care and patient satisfaction. One comparison between a cohort of patients with head and neck cancer who received navigation services and a control group found a clear association

between the presence of patient navigation services and improved continuity of care (Fillion et al, 2009). Another comparison between a navigated Native American group of cancer patients and a control group, found that members of the navigated group had fewer treatment interruptions than members of the control group (Petereit et al, 2008). A randomized study of breast and colorectal cancer patients who were navigated by lay navigators found that navigated patients reported a higher rate of satisfaction with the treatment than non-navigated patients (Fiscella et al, 2012).

However, treatment navigation has not been as effective as screening, diagnosing, and staging navigation. Although one study, treatment navigation resulted in better continuity of care and empowerment for head and neck cancer patients (Fillon, et al, 2009), another study showed that navigation did not generate a significantly higher adherence rate among ethnic and racial breast and gynecologic cancer patients (Ell et al, 2009, Donelan et al, 2011). Furthermore, a comparison between a navigated group and a non-navigated group at a radiation oncology center showed that the percentage of the patients who completed treatment in the navigated group (85 percent) was lower than the percentage of patients in the non-navigated group (95 percent). Patients in the navigated group missed more treatment days (1.86 day per patient) than patients in the non-navigated group (.47 days per patient) (Schwaderer et al, 2008).

These mixed results warrant an examination of PNPs' approach to treatment. Researchers at the Cancer Navigation Program at the University of Rochester derived data on barriers that patients face through a series of semi-structured interviews, and asked navigators to time themselves when addressing each barrier. They found that

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navigators spent more time addressing structural barriers such as employment, than logistical and cultural barriers. Cultural barriers include fear, misconceptions about tests, mistrust of providers, and social support (Hendren et al, 2011). Hence, improving treatment rates requires addressing those cultural barriers.

VI. Addressing The Cultural Barriers

Three of the four frequently cited cultural barriers that lead to treatment disparities among Black American cancer patients are rooted in their religious beliefs. Fatalism, the belief that health outcomes are predetermined by God, inhibits the patients' agency by placing the locus control in an exterior factor (Powe & Finnie, 2003). Lack of social support can result from stigmatizing cancer a punishment for not living according to God's will (Im, 2008). Low self-efficacy is closely related to fatalism in that it inhibits patients' agency. It is also associated with pessimism, which is also a product of believing that cancer is a punishment from God (George et al, 2002). Addressing cultural barriers warrants examining the healing role of religion among Black Americans.

VII. Black Religion, Culture, and Health

Blacks in the United States are more religious than the overall American population. Nearly eight out of ten (79%) of Blacks say religion is very important in their lives compared to 56% among the general population. Blacks attend church services more frequently than Whites. More than half of them (53%) attend church once a week compared to only 39% for Whites. This pattern is consistent even among Blacks who

identify themselves as Christians with no denominational affiliation. Nearly half of unaffiliated Blacks (48%) pray more than twice a day, and 15% attend religious services once a week. In contrast, (22%) of the unaffiliated general population pray more than twice a day, and (5%) attend religious services once a week. Finally, more Blacks (88%) express their belief in God with certainty compared to Whites (71%) among the General population (Sahgal, 2009). Taylor et al (2010), measure religiosity through church attendance (organizational), private prayer (non-organizational), self-assessment of religiosity (subjective). When comparing religious involvement of Black Americans to White Americans, Black Americans had significantly higher levels of organizational, non-organizational and subjective religious involvement (Taylor & Chatter, 2010)

Christianity is more prevalent among Black that the White Americans. While (78%) Blacks belong to various Protestant churches, only (51%) of the overall population do. Conversely, only (12%) of Blacks do not follow any particular denominational affiliation (i.e. unaffiliated) compared to (16%) of the White population. Notably, only (.5%) are Jewish compared to (2%) of the general population, and proportion of Muslims is equal among Blacks and the overall population (1%) (Sahgal, 2009).

Jason Shelton and Michael Emeron (2012) conclude that Black Christian Americans are more passionate about their faith than their White peers. Shelton and Emeron interviewed several clergy members around the United States. Black interviewees tied their higher levels of religiosity to the their historical experience to the persistent racism against Blacks in the United States. The interviewees pointed out the

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racial differences in worship between Black and White Christians (Shelton & Emerson, 2012, 63).

White Christians go about their faith in a formal, doctrine-oriented manner, leaving little room for enthusiastic and spontaneous praise. Their sermons are more structured, focused, and more academic than Black Christians. According to Shelton and Emerson (2012), Whites, on average, take a cognitive approach to faith because they have historically fared well so their approach to God does not to be intense. In contrast, Black Americans go about their faith in an informal, experiential manner where they get to have spontaneous and praise and worship. Their sermons are emotionally charged. Many Blacks take such an experiential approach to faith because they found their liberty through Christ. They would endure the vilest situations because they had hope in God and his justice. Blacks take a need approach to God because they have to ask for safety, food, and shelter (Shelton & Emerson, 2012, 71-77)

Given the importance of religiosity in the lives of many Blacks, it is not a surprise to see how religion plays a central role in their perception of health and that their medical-related decisions revolve around God and religion. Healing through faith is well established in Christianity. Christians who advocate healing through faith refer to the multiple accounts of healing miracles that Jesus performed on individuals with permanent conditions, such as paralysis (Matthew 8:5-17) and blindness (Revelation 21:4). In addition, there are numerous biblical references that encourage faith-healing in the New Testament such as Jesus' promise "They will lay their hands on the sick and they will recover" (Mark 16:18); "…the prayer in faith" (James, 5:14-15); and "Are many

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among you sick? They should call for the elders of the Church and have them pray over them" (New Revised Standard Version). Faith-healing advocates interpret these verses as applicable to all faithful Christians (Mitcham & Townes eds. 2008, p151).

Faith-healing became a popular phenomenon among Black Americans in the late nineteenth century. A group of Black preachers and lay persons began preaching and practicing healing using biblical verses. By the mid 1870s, the phenomenon became a popular movement known as "Healing Movement" through a plethora of healing magazines, conventions, and newspaper articles. The Movement drew practitioners from various denominations, such as Baptists, Presbyterians, and Episcopalians (Mitcham & Townes eds. 2008, p 149). While the Faith Healing movement faded away with the expansion of modern American medicine in the early twentieth century, the idea of using faith and praying to God for healing still exists among Black Americans in varying degrees (Mitcham, 2007, p 50).

A study on Diabetes self-management among Blacks (Campbell, 2007), found that Black participants involved religion in their diabetes self-management according to one of three typologies: In the first typology, participants placed God in the Background. They took charge of managing their diabetes, and looked for God for support. The relation between God and the participants was dynamic in that both took turns in the management process where for every step that participants took in managing diabetes God would follow with another step. Participants described their relation with God as collaborative. In the second typology, participants yielded authority to God by placing him in the forefront while placing themselves in the background. For those participants it

was God who performed the management and improved participants' conditions. These participants described their relation with God as submissive in that he was charge of the management and they were following his directions. In the third and final typology, participants completely relinquished the diabetes management process to God and considered self-management as unnecessary. They believed that if pray to God with a strong enough level of faith, God would initiate the healing mechanisms and heal them from diabetes either instantly or over time (Campbell et al, 2007).

However, the faith-health connection among Blacks contributes to the relatively good health and longevity even among highly religious Blacks for several reasons. First, active involvement in church keeps elderly Blacks survive longer by giving them the feeling that they are part of something vital and making a difference. Second, having a strong faith helps Blacks avoid negative coping with life challenges. Third, highly religious Blacks receive social support from their congregations. Black church has always been a haven that provides its members with support when dealing with difficult times. The support can be emotional, financial, and spiritual. Fourth, highly religious Blacks benefit from the power of prayer. Prayer helps them in casting their burdens on God who is stronger than them, and who can take care of their problems so they don't need to worry about solving them alone. Thus, prayer improves their health because it relieves them from the stress of carrying life's burden, boosts their morale, and gives them a sense of strength of solving their problems through God. Prayer also helps highly religious Blacks in casting their burdens on God who is stronger than them, and

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who can take care of their problems so they don't need to worry about solving them alone (Polzer & Miles, 2007).

VIII. The Role of the Black Church

The Black Church holds the torch for improving the lives of Black Americans by delivering Blacks to "freedom". The church gave the concept of "freedom" a deep religious meaning among Black Americans because it considered freedom a prerequisite to fulfilling the duty to worship God without any constrains. Therefore, freedom took different meanings as the time and context of the Blacks' struggle differed. After the emancipation, freedom meant the right to gain education, employment, and the ability to move from place to place. In the twentieth century, freedom meant economic and political justice. The Church also maintained that if God created people in his image then he must have meant for them to be free (Lincoln & Mamiya, 1990, p 4).

The Church believes that eliminating sickness delivers freedom to Blacks because it allows them to pursue better lives and better worship. The Church also considers health promotion as one aspect of its struggle for freedom. To that end, Black churches have historically played a big role improving the health conditions for the Black populations they serve, and continue to do so through their cancer prevention programs. Black Churches are well suited for improving the treatment rates among Black cancer patients for three reasons. First, they are experienced in addressing the health needs of their communities. Black churches have historically succeeded in improving the health of their communities by running vaccination drives and free health clinics (Benjamins et

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al, 2011). Second, they can reach population segments that would not participate in conventional health programs (Campbell et al, 2007). Third, pastors, who enjoy high levels of trust among congregation members, are experienced in counseling. They counsel individuals on substance addiction, grief, and social relations issues (Young et al, 2003). Pastors are an invaluable resource in counseling cancer patients on the importance of cancer treatment.

The Black church has been instrumental in dispelling myths and providing scientific information about cancer using spiritually-based messages (Holt et al, 2012). The church began to address the cancer disparities among Black Americans through culturally targeted, faith-based programs. Some churches successfully increased the utilization of mammograms and pap smears by facilitating focused group discussions on breast and cervical screening among congregation members. The groups affirmed the role of the church in addressing cancer care as part of their role in caring for the physical and spiritual health of their congregations (Matthews et al, 2006). Other churches successfully increased colonoscopy utilization among their congregation members by conducting church-based educational programs on colorectal cancer. The programs significantly decreased cancer fatalism among participants (Morgan et al, 2010). A community of 20 Black American churches increased prostate cancer screening among their members through spiritually themed health messages coupled with information on prostate cancer (Saunders et al, 2013).

Churches' active involvement in dispelling the myths and educating their congregations about cancer proves that not all Black Americans embrace such myths.

Indeed, not all Black Americans are fatalistic about cancer, have low levels of social support and self-efficacy, or mistrust their physicians. This raises the question, do Black Americans who do not face cultural, socioeconomic, and logistical barriers, have the same cancer outcomes as White Americans? Dr. Otis Brawley made the affirmation "*equal treatment yields equal outcome*". He believes that if none of the barriers mentioned existed, Black cancer patients would have the same treatment as White cancer patients. The following chapter examines this assertion.

IX. Conclusion

Cancer disparities among Black Americans persisted despite the overall improvement of their health that followed the enactment of Medicare, Medicaid, and the community health centers. Attempts to close the persisting cancer disparities through Patient Navigation Programs succeeded in improving the rates of screening and diagnosis, but not the rats of treatment because they focused on mitigating structural barriers. Increasing treatment rates among Black cancer patients requires mitigating the cultural barriers that patients face. Literature cites fatalism, physician mistrust, low levels of social support and self-efficacy as common barriers to treatment.

Examining Black Americans' religious beliefs helps understanding their cultural barriers to treatment since three of these four barriers are rooted in myths around Black Americans' religious beliefs. Most of Black Americans embrace Christianity, and some Black Americans rely on faith for healing citing the numerous biblical references to healing in the Bible. The idea of healing through faith was the basis of the "Faith

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Healing" movement, which gained prominence in late nineteenth century but faded away with the expansion of modern medicine. Some Black patients, however, still use faith healing in varying degrees.

Dispelling the myths surrounding Blacks' cultural beliefs entails involving the Black church in educating their congregation members and promoting cancer treatment. The Black church is well suited for advocating treatment because of it historical experience in improving the health of its congregation members. Historical experience proves that not all Blacks embrace the myths surrounding cancer treatment, which raises the question if Black cancer patients receive timely treatment have the same outcomes as White cancer patients. Dr. Otis Brawley affirms the notion of "*Equal treatment, equal outcome*", indicating that giving Black cancer patients the same levels of cancer care will eliminate the disparities.

Chapter Three

Methodology

I. Introduction

The present research combines postpostivitst and pragmatic worldviews to assess Black Americans' cultural attitudes towards cancer in relation to those of White Americans. The postpostivitst worldview challenges the claim that all Black Americans share the same cultural attitudes towards cancer, and that their cancer-related cultural beliefs differ from White Americans' cultural beliefs. The pragmatic worldview what shapes Black Americans' views on cancer diagnosis and treatment.

The present research is based on the answers and narratives of fifteen Black and fifteen White American cancer survivors, and it employs a combination quantitative and qualitative analysis methods. The quantitative method utilizes a two-tailed T test to compare average responses of four survey instruments that measure participants' levels of fatalism, physician' trust, social support, and self-efficacy. The qualitative method utilizes the Constant Comparative Analysis of participants' narratives also to measure the levels of the same four cultural attitudes.

II. Philosophical Worldview

A philosophical worldview is the basic set of beliefs that guides research design and choice of methodology. Researchers, student advisers, and mentors base their work on four main worldviews: positivism/postpositivism, constructivism, transformational, and pragmatism. Positivism dominated western science between 1615 and 1920s, and it represents the basis of the traditional scientific inquiry. Positivism generates knowledge by putting forth hypotheses and developing numerical measurements of researchers' observations. Positivist researchers test their hypotheses by obtaining empirical findings under controlled conditions. They tend to be reductionists as they concentrate on a single hypothesis, which automatically eliminates simultaneous observations and alternative hypotheses (Clark, 1993).

Postpositivism emerged after the 1920s as a modified version of positivism. It rejects the notion of generating knowledge under controlled conditions, and believes that testing hypotheses must take place under natural and realistic conditions in order to generate true knowledge. It also rejects reductionism and accepts multiple observations and alternative hypotheses. Researchers with postpostivitst worldview seek to gain an objective understanding of reality by developing numerical measurements of their observations, just like positivist researchers do. However, they account for the influences of natural surroundings, and offer multiple explanations for their multiple observations when reaching their conclusions (Creswell, 2014, 7, Clark, 1993).

Some positivist researchers put forth a reductionist view of Black Americans by generalizing their views to encompass all Black Americans (Freeman, 2006; Gerend &

Manacy, 2007; Guildy, J. J. et al, 2003). For example, in discussing the role of culture for Black American women's health seeking behavior, Guildry states:

Although there is as much heterogeneity among these women as there is among women of other ethnic groups, there remains a set of shared beliefs, values, and experiences that researchers should understand when evaluating the importance of culture in breast cancer prevention and control.

Guidly's assertion that Black American women share the same beliefs towards cancer diagnosis, despite their heterogeneity is a reductionist one. It may lead to the assumption that all Black American women have the same health seeking behavior towards cancer. However, some evidence points to the contrary. Black American women, and men, who receive the same timely cancer treatment as White Americans, have the same survival rate as White Americans (Siegel et al, 2014). For example, Black and White members in the military, with similar access to health care facilities, have similar cancer outcome and similar mortality rates as their White counterparts (Ashish et al, 2001 & Zheng el al 2012).

The present research challenges the knowledge claim that Black Americans' cultural beliefs prevent them from seeking cancer treatment. The postpostivitst approach in this research utilizes objective measurements to compare the cultural beliefs of Black and White cancer survivors, as the positivist approach does, but it accepts alternative observations and multiple explanations. This approach breaks Black Americans' cultural beliefs into discrete elements and compares these elements, through quantitative measures, to White Americans' cultural beliefs relating to cancer

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treatment. The approach produces an objective conclusion about the role that Black American cultural beliefs play in their treatment seeking behavior.

The pragmatic worldview takes into consideration the social, historical and political contexts of the social problem at hand and utilizes both quantitative and qualitative methods to understand and solve the problem (Crewell, 2014, 11). In contrast to postpostivism, which seeks to prove a hypothesis as true or false, pragmatism sidesteps the true/false dichotomy and accepts the view that there are multiple interpretations of reality. It seeks to produce knowledge that represents such different interpretations. The pragmatic worldview focuses on how the research can be useful for a social population. It studies how some of the population members handle the problem in question and uses its findings to solve the problem for the larger social population (Feilzer, 2009). In the case of the present research, the pragmatic worldview analyzes the narratives of Black American survivors, who received adequate and timely cancer treatment, to find how these survivors overcame screening and treatment disparities. Findings of this research inform the larger Black American population on how to overcome the cultural attitudes that lead to cancer disparities.

The constructivist worldview is not appropriate for this study. This worldview seeks to interpret the world from the perspective of a studied social group, and to develop a subjective understanding of the life and work experiences of the studied group members. Researchers in this worldview inductively develop a theory or pattern rather than starting with an existing one as in the postpositivist worldview (Creswell, 2014, 8). The present research does not seek to interpret the reality of cancer

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disparities from the perspective of Black survivors, nor does it seek to develop a theory on how Black American cancer survivors interpret cancer disparities. The research seeks to compare the levels of cultural attitudes between Black and White American cancer survivors, and to explore how Black American survivors can overcome such attitudes. Therefore, this research cannot be based on the constructivist worldview.

The transformative worldview approach arose in the 1980s from groups and individuals who felt marginalized by the existing laws and social norms, such as persons with disabilities and indigenous populations around the world (Creswell, 2014, 9). Researchers with the transformative worldview begin with certain issues of social justice as focal points of their studies, and then they inquire about political processes and policy changes that achieve the desired social change. They collaborate with the studied populations in designing the research by allowing population members to design the research questions, collect and analyze data, and make conclusions (Creswell, 2014, 10). The transformative worldview is not appropriate for this research. Although this worldview approach focuses on marginalized social groups, such as racial minorities, it may offer inaccurate results. Its method is not feasible for this research since study participants do not have the social networks, or the technical knowledge that allow them to measure the cultural attitudes Black Americans' relating to cancer treatment or investigate their mechanisms in combating cancer disparities.

To summarize, the present research is guided by two worldviews: The postpositivist worldview challenges the positivist thinking that generalizes cultural attitudes of all Black Americans relating to cancer treatment. This worldview breaks

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cultural attitudes to discrete elements and compares them to the cultural attitudes of White American cancer survivors. The present research is also guided by the pragmatic worldview. This worldview seeks to inform the Black American population on how to overcome cultural attitudes that hinder seeking cancer treatment by examining the attitudes of Black American cancer survivors who received adequate and timely treatment.

III. Research Questions and Hypotheses

After deciding on the postpositivist and pragmatic worldviews to conduct the research, I move to the next step of identifying the research question and hypothesis. The present research asks: "Do Black Americans' cultural beliefs hinder their cancer treatment seeking behavior in comparison to White Americans? The question hypothesizes that if Black Americans have the same cultural beliefs as White Americans, then they receive cancer treatment. Cultural beliefs in this context refer to fatalism, mistrust of providers, social support, and self-efficacy. Fatalistic individuals are less likely to seek treatment because of their pessimism about the outcome of their cancers, which stems from the conviction of the futility of treatment. Such individuals feel powerless as they believe that the outcome of their diagnosis is determined by a higher power and cannot be changed through treatment (Powe, 1995). Individuals who mistrust their physicians are also less likely to receive treatment. They dismiss their physicians' advice on how to treat cancer because they believe that such advice serves the physicians' interests rather than their own (Whetten et al, 2006). Low levels of social

support decrease individuals' ability to seek treatment because they deprive them from the help they need to deal with their diagnoses. They also increase their susceptibility to adverse health consequences such as depression and alcoholism, which may ensue from the onset of a cancer diagnosis (Cobb, 1976). Finally, low levels of self-efficacy reduce individuals' ability to seek treatment. Individuals with such levels doubt their ability to communicate with their providers and their ability to make decisions concerning cancer treatment (Anderson, 2006).

Individuals may hold the cultural beliefs mentioned above in varying levels. Higher levels of fatalism and physician mistrust, and lower levels of social support and self-efficacy, are associated with lower levels of adherence to cancer treatment (Powe,1995; Whetten et al, 2006; Cobb, 1976; Anderson, 2006). Given how these four cultural beliefs hamper individuals' ability to seek cancer treatment, I break the research question to four sub questions. Each sub question addresses one cultural belief:

1. Are Black American cancer survivors as fatalistic as White American cancer survivors?

2. Do Black American cancer survivors trust their physicians as much as White American cancer survivors do?

3. Do Black American cancer survivors have the same level of social support as White American cancer survivors?

4. Do Black American cancer survivors have equal levels of self-efficacy as White American cancer survivors?

I derive the following hypotheses from the above questions:

5. Black Americans cancer survivors who receive treatment are equally as fatalistic as White American cancer survivors.

6. Black American cancer survivors who receive treatment trust their physicians as much as White American cancer survivors do.

7. Black American cancer survivors who receive treatment have equal levels of social support as White American cancer survivors.

8. Black American cancer survivors who receive treatment have equal levels of self-efficacy as White American cancer survivors.

IV. Variables

From these questions, I isolate two types of variables, independent and dependent. The independent variable is the factor that I hypothesize it influences survivors' cultural attitudes. I isolate the race of cancer survivors, whether Black or White Americans. The dependent variable is the factor that I hypothesize it is influenced by the dependent variable and it affects survivors' treatment-seeking behavior. I isolate the levels of fatalism, physician mistrust, social support, and self-efficacy as four dependent variables. These levels can be low, medium, or high. Historically, low levels of physician trust, social support, and self-efficacy have been associated with lower treatment rates. High levels of fatalism have been associated with low treatment rates (Powe, 1995).

1. *Fatalism*

Fatalism is belief that death is inevitable when a serious disease is present. It encompasses such dimensions as pessimism; the perceived sense of powerlessness, hopelessness, and the notion of destiny and predetermination of the negative health condition. In the case of cancer, fatalism encompasses three components: 1) the predetermination component means that the cancer diagnosis is unavoidable; 2) the powerlessness and hopelessness dimension means that the diagnosis is untreatable; and 3) the pessimism dimension means that the diagnosis always leads to death. Therefore, the fatalism variable measures the belief in the 1) certainty of getting cancer, 2) the inability to treat it, 3) and the belief in the certainty of dying from it (Shen et al, 2009). Survivors' level of fatalism is a composite score of a 15-item questionnaire that measures the three dimensions. Survivors can score up to five points for each item, and up to 75 points for the entire questionnaire. I consider survivors with scores of 25 points or less to have low levels of fatalism, survivors who scores between 26 and 50 points to have medium levels of fatalism, and survivors who score 51 to 75 points to have high levels of fatalism.

2. *Self-Efficacy*

Self-efficacy is an individual's own perceived ability to perform a specified behavior, or set of behaviors (Anderson, 2006). It is product of a reciprocal interaction between behavior and outcomes: Individuals learn self-efficacy when they act in a certain manner and receive certain expected results in return. They develop confidence

in their ability to attain their desired outcomes when their behaviors consistently result in such desired outcomes. For example, cancer patients who consistently receive treatment when they ask their doctors for it develop self-efficacy. For these patients, self-efficacy directly affects the ability to effectively communicate with health care professionals, engage in the treatment decision and management, and develop a positive attitude because of the confidence they have in receiving the needed treatment. The combination of these elements of enhances the quality of treatment decision-making and adherence to clinical recommendations and treatment regimen (Wolf et al 2005).

Accordingly, the self-efficacy variable comprises of three elements, 1) maintaining a positive attitude, 2) communicating with health care professionals by asking questions and obtaining information, and 3) participating in making decisions relating to cancer treatment (Wolf et. al., 200s). Survivors' level of self-efficacy is a composite score of a 12-item questionnaire that measures the three elements. Survivors can score up to five points for each item, and up to 60 points for the entire questionnaire. I consider survivors who score 24 points or less to have low levels of self-efficacy, survivors who score between 25 and 45 points to have medium levels of self-efficacy, and survivors who score 46 to 60 points to have high levels of self-efficacy.

3. *Social Support*

Social support is the information that leads subjects to believe that they are cared for, loved, and that they belong to a network of mutual obligations. This belief can

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reduce the adverse health consequences that ensue from crises, such as depression, alcoholism, tuberculosis, or even death. In addition, social support enhances recovery from a health crisis and reduces the amount of needed medication for recovery (Cobb, 1976). Social support comprises of three components: 1) emotional, 2) material, and 3) cognitive support. Emotional support refers to empathy and encouragement received during personal visits and phone calls that participants received. Material support includes help with transportation and living expenses and wound dressing. Cognitive support includes giving advice about treatment (Balgrave & Lewis, 1994 & Gallant, 2003). Hence, the social support variable measures the levels of the three components of social support they received from their community. Survivors' level of social support is a composite score of three components on a 10-item social support measurement questionnaire. Survivors can score up to five points for each item, and up to 50 point for the entire questionnaire, I consider survivors who score 20 point or less to have low levels of social support, survivors who score between 21 and 38 points to have medium levels of social support, and survivors who score 39 to 50 points to have high levels of social support.

4. *Mistrust of Physicians*

Historically, physician mistrust was a product of White medicine's long history of racism against Black Americans. Black folk stories about White medicine exploitation of Black Americans have fueled provider mistrust in the past (Gambel, 1997). More recent research shows that mistrust is influenced by physicians' financial concerns and lack of

competence rather than by racism (Jacobs, 2006). It also shows that the level of mistrust due to lack of competence is equal between minority and nonminority patients (Whetten et al, 2006).

The Physician-trust variable captures the two main elements that foster trust: putting patient needs first and competence. The variable measures 1) whether participants believe that their physicians make decisions based solely on their medical needs, and 2) whether participants believe that their physicians are competent. Physicians' competence is directly related to their interpersonal capabilities that include communication skills. Competent medical care entails gathering accurate medical details, making appropriate judgment about the appropriate course of care, and giving patients the information they need for effective treatment. This information includes timely and accurate diagnosis as well as appropriate advice. Hence, trust in physicians' competence entails trust in their judgment and advice (Hall et al, 2001). Survivors' level of physician-trust is a composite score of the two elements using an 11-item questionnaire. Survivors can score up to five points for each item, and up to 55 points for the entire questionnaire. I consider survivors who score 22 points or less to have low levels of physician trust, survivors who score between 23 and 42 points to have medium levels of physician trust, and survivors who score between 42 and 55 points to have high levels of physician trust.

V. Data Collection Method

Upon receiving Institutional Review Board approval, I recruited a convenience sample of 30 participants, 15 Black and 15 White participants with a cancer history. The participants come from a suburban, predominantly White community, with a small minority population (90.8% White, 5.5% Blacks, 3.7% other) (U. S. Census Bureau, 2014). I recruited a total of 28 participants from local urology, gynecology, and oncology practices, and two participants from the Hernando County Health Department and USFTalk, a University of South Florida online forum.

I began the process with reaching out to local physicians in Hernando County and their staff members, explaining the research nature, and asking for their assistance in recruitment. Staff members filtered their patient database to find potential participants who have been treated for cancer. Given the small percentage of Black Americans in Hernando County (5.5%), I asked the staff members to locate Black participants first, and then locate White participants with matching demographic and health characteristics. Staff members explained the research to the prospective participants and provided them with my contact information to set up an appointment with me for an interview. Staff members also notified prospective participants about a twenty-five dollar incentive that they would receive at the end of the interview. The same process took place with the Hernando County Health Department.

After setting the appointments, I conducted face-to-face interviews with participants in public places such as Panera Bread, Starbuck Coffee shops, or at the public library. In some cases, I met with participants in their homes to administer

research instruments. The interviews lasted between 20 and 60 minutes. All participants reviewed the research information and consented to the interviews. I recorded the interviews and transcribed them verbatim for analysis.

Members of the two groups matched each other in cancer history, age, socioeconomic status, marital status, and education level. Race was the only difference as one group consisted of Black and one of White participants. Each group consisted of two breast cancer survivors (age 70-70, and age 50-59), two female colorectal cancer survivors (age 50-59), one male bladder cancer survivor (age 60-69), one endometrial cancer survivor (age 30-39), one female brain cancer survivor (age 30-39), and eight prostate cancer survivors (age range 50-79). Most participants had stage one while only three pairs of participants had stage two cancers (2 pairs with breast cancer and 1 pair with endometrial cancer). The survivors' incomes in each group ranged between ten thousand and ninety thousand dollars, and their education level ranged between high school and four years of college. All the participants had Medicare, Medicaid, private insurance, or a combination of insurances. None of them, however, reported having a problem with covering treatment costs. The attached table in appendix 1 lists all participants demographic, socioeconomic, educational, and cancer data.

VI. Research Instruments

I employed a combination of qualitative and quantitative research methods in the research. Quantitative methods rely on mathematical approaches to produce numerical data. They have long been used to in natural sciences, and have been considered as

the mainstream approach for conducting and reporting scientific research and findings. For example, quantitative methods provide statistical data on fatalism levels among Black and White cancer survivors and compare those levels numerically. The quantitative portion of this research comprises of closed-ended questions that measure participants' levels of fatalism, trust of providers, social support, and self-efficacy. They are listed in appendix 2 (Roberts et al, 2006).

Qualitative methods rely on recording observations of studied subjects in order to explain certain phenomena. These methods produce descriptive, rather than numerical data that detail participants' views and behaviors (McKinnon, 1998; Flick, 2014, 13). For example, qualitative methods use Black cancer survivors' narratives to explain *why* cancer these survivors become fatalistic, and explore *how* they minimize their fatalism levels. The qualitative method in this research is comprised of open-ended questions about the participants' views and experiences with the cancer diagnosis and treatment, their sources of influence on health behavior, and their coping strategies with their diagnoses (Beitin 2012).

A combination of quantitative and qualitative methods produces more nuanced knowledge about social phenomena than either method does individually. In the example of fatalism among Black cancer survivors, the combination provides the statistical data about fatalism levels among Black cancer survivors in comparison to their White counterparts, while providing descriptive data that illustrate how Black survivors minimize their fatalism levels (Johnson et al., 2007).

VII. Rigor in the Quantitative Method

Reliability and validity are ways of demonstrating the rigor of the research measurements. It describes how far a particular research tool, such as questionnaire, produces similar results in different circumstances. Validity is a subtler concept than reliability. It describes the closeness of what the research actually measures to what it intends to measure. A study is invalid if its design or conduct are such that they measure more than or less than the research claim (Roberts et al, 2006).

Each of the instruments that I have chosen to measure the cultural beliefs in question has been tested for validity and reliability through psychometric analysis. A psychometric analysis is an objective measurement approach that measures individuals' skill, abilities, attitudes, and knowledge. It is used in social sciences to measure instruments for validity and reliability using techniques such as regression, correlation, and factor analysis; and by utilizing various software including SAS, SPSS, and DIMTEST (Price, 2016).

For fatalism, this study used Powe's Cancer Fatalism Test, (mPFI) which is a 15-point questionnaire statement that examines the three elements of fatalism (Appendix 2). Statements 1, 3, 4, 5, 9, 13, 14 address the unavoidability element. Statements 6, 7, 8, 10, 11, 15 address the association with death element; and Statements 2,12 address the un-treatability element. The questions take different formats to ensure that participants give consistent answers. Psychometric analysis measuring the link between intent to seek treatment and above-mentioned elements determined that the mPFI instrument is valid and reliable (Shen L, 2009). mPFI is measured on a 1-5 Likert Scale,

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where 1 means very low, 2 means low, three means medium, 4 means high, and 5 means very high. Higher scores denote higher levels of fatalism.

The trust-of-physician scale is an eleven-statement scale that assesses whether participants believe that their physicians make decisions based on their needs, and whether they believe in their competence (Appendix 2). Statements 1, 2, 7, 8, 11 address the patient needs element, statements 3, 4, 5, 6, 9, 10 address the medical competence element. The Physician Trust instrument has already been tested for validity and reliability by measuring the correlation between patient perceptions of physician competence and concerns on one hand, and patients' trust in physicians on the other hand (Freburger, 2003 & Rose et al, 2004). Participant responses to the physician trust scale are measured on the Likert Scale where 1 means very low, 2 means low, 3 means medium, 4 means high, and 5 means very high. Higher scores denote higher levels of physician trust.

The modified Duke-UNC Functional Support instrument measures the levels of social support participants receive. It lists a total of ten statements about whether participants received as much as, or less than they would like material, cognitive, and emotional support (Appendix 2). Statements 3, 6, 10 focus on material support, statement 8 focuses on cognitive support, and statements 1, 2, 4, 5, 7, 9, focus on emotional support. The psychometric analysis of the social support elements indicates that theDuke-UNC instrument is valid and reliable (Broadhead et al, 1988, Belgrave & Lewis 1994).

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Participants expressed their satisfaction by reporting if they received as much support as they would like for each component using a 1-5 Likert Scale, with 1 being not nearly as much as they would like, 2 not as much as they would like, 3 not sure, 4 somewhat as much as they would like, and 5 as much as they would like.

Finally, the Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer) measures the self efficacy variable. The scale consists of twelve statements that measure the three elements of self-efficacy. Statements 1through 4 address the participating in treatment element, statements 5 through 8 address the positive attitude element, and statements 9 through 12 address the seeking information element. Psychometric analysis determined that CASE-cancer is valid and reliable (Wolf et al, 2004).

Participants' responses to statements that measure the three elements are graded according to the Likert Scale with 1 means very low, 2 means low, three means medium, 4 means high, and 5 means very high. The sum of all participant responses makes up final self-efficacy level for that participant.

VIII. Quantitative Data Analysis

I measured participants' responses for the four scales on a 5-point Likert scale. The sum of response points in each instrument indicates each participant's level for the said instrument. Then, I calculated the means values for each instrument for each racial group by adding together all the sums then dividing their total by 15, which is the number of participants in each racial group.

The quantitative analysis compares the means values of participants' responses to the survey instruments. For each survey instrument, I entered Black participants' sums of responses in one column and White participants' sums of responses in another column in the VasserStat software's t-test calculator. I consider Black participants to have different cultural attitudes when the differences in Means values of their responses [Means (B) – Means (W)] are statistically different from the Means values of White Participants' responses. The statistical formula for this consideration is:

Ho: M (B) = M (W) and

Ha: M (B) ≠ M (W)

Where Ho is the null hypothesis stating that Black participants have the same cultural attitudes as White participants. Conversely, Ha is the alternative hypothesis that states that Black participants have different cultural attitudes than White participants

I used an unpaired, two-tail t-test, with an assumption of 95% confidence, which means that the probability (ρ) of a type I error is ($\alpha = .05$). A type I error occurs when a null hypothesis is rejected even though it is true. It results in accepting an alternative hypothesis despite being attributable to chance. Therefore, if (ρ) is more than (.05), then I consider that the differences in Means values are attributed to cultural differences between Black and White participants rather than a chance. In statistical terms:

Ho: M(B) – M(W) > .05 then Black participants have the same cultural attitudes as White participants.

Ha: M(B) – M(W) ≤ .05 then Black participants do not have the same cultural attitudes as White participants

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The t-test has two variations and determining which variation of t-test is appropriate depends whether variances are equal. I conducted an F-test to determine whether variances are equal before conducting the t-test. I conducted the student t-test when variances were equal, and conducted the Welch t-test when they were not.

IX. Rigor in the Qualitative Method

Ensuring validity and reliability in the quantitative research guarantees the research objectivity and rigor. For qualitative analysis, it is dependability and conformity that ensure rigor and objectivity. The term *dependability* in qualitative analysis corresponds with the term reliability used in the quantitative analysis. It refers to processes and procedures that make the research consistent and produce trustworthy findings. Similarly, the term *conformity* in qualitative research corresponds with the term validity to describe how the research studies what it claims to study (Zhang et al, 2009). I utilized the following five strategies that ensure dependability and conformity in the open-ended questions that I formulated for qualitative analysis (Appendix 3):

I ensured methodological coherence, which refers to the congruence between the research question and components of the method by utilizing focused peer review of the survey instrument (Morse et al, 2002). A focused peer review is a process in which a group of peers conducts a review of a particular work to identify potential problems. Three of my PhD student colleagues reviewed the questions and provided feedback on how they understood them. They suggested the following changes to ensure that the wording of the questions matched their intended meaning: For question 5, they suggested adding the question "were they supportive?" to focus on the support variable.

They also suggested adding question 6 as a follow up to question 5 for answer consistency. Finally, they suggested adding the last question "Is there anything that you would like to add?" to give participants a chance to add any thoughts to their narratives.

After making the changes that my colleagues suggested, I conducted pilot testing with three racially diverse volunteers to ensure cultural appropriateness. I read the instrument questions to two Black female and two White male sophomore students at the University of South Florida. The volunteers approved the instrument format and presentation. (Bowden et al, 2002). I also, used various formats for each question to ensure internal consistency. For example, when I asked participants about their first reaction about their diagnosis, I asked them: *"What was your first reaction when you found out you had cancer?"*, then I followed up with "*What was the first thought that came to your mind?*"

X. Qualitative Data Analysis

I utilized the Constant Comparison Method (CCM) for the qualitative analysis. CCM is a qualitative approach that depends on comparing newly collected data to existing data to discern conceptual similarities and discover patterns. It allows the researcher to decide what data to look for and collect to confirm provisionary ideas (Boeije, 2002). In this analysis, the CCM method was useful for identifying the elements of dependent variables, and for discovering the how Black participants differed from White participants in coping with their diagnoses.

After transcribing the first participant's narratives and answers to the open-ended questions, I assigned different colors for different themes in the participant narratives (Kolb, 2012). For example, as I read the interview transcripts, I highlighted all statements relating to positive attitude with purple, all statements relating to communicating with physicians with yellow, and all statements relating to making decisions with light red. Then I categorized all statement themes under their responding cultural attitudes and tallied the number of themes in each category. For example, I categorized all purple, yellow, and light red highlighted theme statements under "self efficacy." As I interviewed the second participant, I compared her statements relating to the self-efficacy variable to the first participant statements, and used the same highlight color for matching statements. I continued the same process for all participants. Then, I tallied the number of each cultural attitude under each category for each interviewee and compared the number of tallies between Black and White. In addition, I compared how Black participants' statement contents differed from those of White participants.

XI. Conclusion

The present research is embedded in the postpositivist and pragmatic worldviews which challenges current claims of knowledge and examine the role of religion in shaping Black Americans' cultural attitudes on cancer in relation to White Americans. Both quantitative and qualitative instruments are applied to provide a wider perspective on the findings. The research design follows the required criteria that ensure objectivity in each method.

The present research hypothesizes that if Black Americans receive cancer treatment then their levels of fatalism are as low as the levels of fatalism among White Americans; and if Black Americans receive cancer treatment then they have equal levels of social support, physician trust, and self-efficacy as White Americans. To confirm the hypotheses, the current research analyzed statements and survey questions of 30 Black and 30 White cancer survivors using the Constant Comparison Method and a two-tailed T survey instruments for the qualitative and quantitative methods respectively.

Chapter Four

Quantitative Results

I. Introduction

The literature indicates that disparities in cancer screening and treatment persist between Black and White Americans. These disparities lead to higher mortality cancer rates among Blacks. Cultural barriers, including fatalism, mistrust of physicians, low levels of social support, low levels efficacy in making treatment decisions are frequently cited as cultural attributes that hinder Blacks from cancer screening (Jerant et al, 2008, Gerend &Pai, 2008, Paskett et al, 2011).

In his editorial in the "*Cancer Journal for Clinicians*", Dr. Otis Brawley (2008) argues that these cultural causes can be changed because they are extrinsic to the Black human body. He advocates cancer screening to the Black population as a whole, regardless of their socioeconomic status. Dr. Brawley believes that this prescription to the Black population will change their cultural attributes. (Brawley, 2008).

The current research· investigates if the cultural attributes mentioned above can be changed to become similar to the cultural attributes of White cancer survivors. To test Dr. Brawley's prescription, a sample of Black and White cancer survivors with

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· The research has been approved by the Institutional Review Board. IRB #: Pro00015100.

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similar socioeconomic status is recruited for the research. Both Black and White individuals recruited for the study have been treated for cancer. Based on Dr. Brawley's prescription, the research hypnotizes that sampled Black cancer survivors have similar cultural attributes to the sampled White cancer survivors.

II. Research Hypotheses

The study compares levels of fatalism, physician trust, social support, and self-efficacy between a sample group of Black cancer survivors and a control sample of matching White cancer survivors. Both groups have received cancer treatment. The study controls non-cultural attributes, including socioeconomic and demographic factors, as well as for cancer types and stages.

The current study hypothesizes the following:

1. If Black American cancer survivors receive treatment then they are equally fatalistic as White American cancer survivors.

2. If Black American cancer survivors receive treatment then they trust their physicians equally as White American cancer survivors.

3. If Black American cancer survivors receive treatment then they have an equal amount of social support as White American cancer survivors.

4. If Black American cancer survivors receive treatment then they have equal amount of self-efficacy as White American cancer survivors.

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III. Source of Data

Two groups of individuals, one Black and one White, who have been treated for cancer were recruited. Each group consisted of fifteen self-selected participants with matching diagnoses, age, socioeconomic status, and gender. Participants were recruited from private urology, gynecology, and oncology practices in Hernando County, as well as from USF Talk, a University of South Florida listserv. During their face-to-face interviews with the researcher, the participants provided quantitative data by completing four survey instruments: Powe's Fatalism Scale Instrument (Powe,1995), which has15 items, Physician Trust Scale Instrument (Freburger et al. 2003), which has10 items, Duke-UNC Functional Support Scale Instrument (Broadhead et al,1988), which has 11 items, and CASE-Cancer Self-Efficacy Scale Instrument, (Wolf et al 2005), which has12 items. Study participants were asked to respond to the items in these instruments using a five-point Likert scale ranging from 1(strongly disagree) to 5(strongly agree). The sums of participant responses were recorded in the tables on pages 4 thru 7. The Instruments are presented in appendices 1 thru 4.

IV. Method

The study compares participants' cultural attributes by comparing the score Means of the four survey instruments they completed. Black participants are considered to have the same cultural attributes as White participants if the unpaired, two-tailed- t-test, yields no significant difference between the participants' score Means [Mean (b) –

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Mean (w)]. The significance test assumes a confidence level of 95%, which means that the risk of a Type I error is (α=.05). A Type I error occurs when a null hypothesis is rejected even though it is true. The error results in accepting the alternative hypothesis despite being attributed to chance. In other words, probability (p) value that is less than .05 indicates that the Means difference is significant, and not attributable chance, and thus, it is attributable to cultural differences between the two racial groups. In contrast, a probability (p) value that is higher than .05 (p >.05) indicates a non-significant Means difference. It indicates that the means difference between the two racial sample groups could be attributable to chance.

Determining which t-test is appropriate depends on whether the variances between the scores are equal. The Student's t-test is appropriate for equal variances while the Welch t-test is appropriate for unequal variances. Therefore, conducting an F-test to see whether variances are equal is the first step towards comparing Means

V. Results

The sums of participants' responses for each scale are entered into Vasserstat.net software (Lowery, 2015) to compare each of the cultural attributes mentioned above for the two racial groups. Vasserstats calculates the "Mean" value for each group sample, with the assumptions that the samples have equal and unequal variances. It also calculates the difference in the Means values for both group samples, and the p value, under both assumptions.

1. Fatalism

Each number in Table 2 represents a participant's sum of responses of Pow's fatalism survey instrument. The first column contains Black participant responses and the second column contains White participant responses. The F-test indicates that the variances are equal between the two sample groups ($p > 0.174265$). Further, the mean values between the two columns Mean(b) – Mean(w) = 5.1333. The t-test shows no statistical significance between the two mean values ($p > 0.187057$). Therefore, we fail to reject the null hypothesis, which states that Black cancer participants, are equally fatalistic as White cancer participants.

2. Physician Trust

The F-test shows for the physician trust scale (Table 3) shows that variances are equal between the two samples ($p = 0.108484$). The mean of Black participants' levels of physician trust is lower than the mean of White participants' by 1.8. However, this difference is not statically significant as the t-test indicates ($p = 0.454871$). Therefore, we fail to reject the null hypothesis, which states that Black cancer survivors, who received treatment, have the same levels of physician trust as White cancer survivors.

3. Social Support

Black and White participant sums of responses for the Social Support survey Instrument are entered in their respective columns in the table above. The F-test shows different variances between the two groups ($p = 0.042892$) (Table 4). However, there is

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no statistical difference in the mean values of the two sample groups (-1.66) since p >
.05 (p = 0.483145). Therefore, we still fail to reject the null hypothesis, which states that
Black and White cancer survivors have an equal level of social support.

4. Self-Efficacy

The variances are equal between Black and White Black participants' self-
efficacy Mean scores (p = 0.423971) (Table 5). The t-test shows that Black participants
have, on average, higher levels of self-efficacy than White participants as the difference
in the Means values (2.13) indicates. Since the p value is higher than .05 (p >
0.311526), we conclude that the mean difference between the two groups is not
statistically significant. Accordingly, we fail to reject the null hypothesis, which states
that Black and White cancer survivors have an equal level of self-efficacy is.

VI. Discussion

The differences in means values between Black and White participants are
higher for fatalism and self-efficacy and lower for physician trust and social support.
These differences indicate that Black participants had higher levels of fatalism and self-
efficacy, but lower levels of physician trust and social support. However, these
differences do not represent cultural dissimilarities between Blacks and Whites in the
studied population. They remain within the normal distribution ranges of the total
population that participants were recruited from, as the p values illustrate. In addition,
with the exception of social support, mean score variances were equal between the two

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groups. These results reveal that Black and White populations from which the sample was drawn, have similar cancer-related attitudes.

VII. Conclusion

The quantitative analysis investigated cancer-related cultural differences between Black and White cancer survivors. It focused on the levels of the frequently cited differences in fatalism, physician trust, social support, and self-efficacy. Fifteen Black and fifteen White cancer survivors participated in the study and answered survey instruments for the said four attributes. Vasserstats software was used to calculate the F and t scores for each of the four survey instruments. Results show that with the exception of the Social Support scale, participants' Mean scores are equal. In addition, t-test results show that although Black cancer survivors who participated in this study have higher levels of fatalism, and self-efficacy, and lower levels of physician trust and social support than White participants, the Means differences were not statistically significant. Therefore, I conclude that Black and White cancer survivors with similar socioeconomic status, and who have been treated for cancer, are considered to have similar levels cultural attitudes relating to cancer diagnosis and treatment. This study is consistent with Dr. Brawly's belief that cultural attitudes are extrinsic to the Black human body and not all Black Americans hold them. However, proving Dr. Brawly's belief requires a longitudinal study of a random sample that includes changing the socioeconomic status, and observing the responding change in cultural attributes. The next chapter will take a closer look at differences in cultural attributes by conducting a

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qualitative analysis of participants' attributes towards the various dimensions of each of the survey instruments used in this chapter.

VIII. Limitations:

The study is limited by the self-selected nature of the population sample, which makes the sample not randomized. It is also limited by the small sample size used to conduct the study. In addition, study sample included participants who received successful treatment, which limits applicability of the study to Black Americans who received treatment only. Further studies, with more randomized and larger, more representative samples are needed to confirm study results.

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Chapter Five

Qualitative Results

I. Introduction

The Quantitative analyses conducted in the previous chapter confirmed the four hypotheses stating that Black cancer survivors, with similar socioeconomic status, have the same cultural attributes (fatalism, physician trust, social support, and self-efficacy) towards cancer as White cancer survivors. The qualitative study in this chapter will re-test the four hypotheses by conducting a content and discourse analyses of the survivors' statements on the cultural attributes in question.

The chapter will start with interview summaries and comparisons between the cancer experiences of Black and White survivors who participated in the study. Black and White participants with similar socioeconomic status and cancer types narrated their experiences by answering a series of open-ended questions about to their diagnoses and how they dealt with them. The participants also talked about the social support they received from family and friends throughout the cancer ordeal. Finally, the participants reflected on their experiences by advising future cancer patients on how to handle a cancer diagnosis.

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The study will classify and list participant statements according to the dimensions of each of the cultural attributes used in the quantitative survey instruments. The fatalism instrument has three dimensions: belief in the predetermination of cancer, belief in (bad) luck in being diagnosed with cancer, and pessimism about the cancer diagnosis. Accordingly, each of the participants' statements relating to fatalism will be listed under its corresponding dimension. Similarly, the provider trust instrument has three dimensions: trust in provider's technical competency, trust in provider's care for patient needs, and trust in provider's honesty in delivering medical advice. Participants' statements relating to provider trust will be classified by the trust dimensions they address. Statements relating to social support will be classified depending whether they discuss cognitive, emotional, or material support. Statements on self-efficacy will be classified under positive attitude, seek and communicate information, and make health decisions.

Upon classifying all relevant statements, the study will analyze Black and White participant accounts in the various dimensions by examining their sentence structures and choice of words. Then, the study will compare the cultural attributes of the two racial groups by comparing their statements on each dimension of the four cultural attributes in question. Finally, the study will draw a conclusion on the similarities and differences of cancer-related attributes between the two sample groups.

II. The Role of Religion in the Black Population Health

Blacks in the United States express a higher level of religiosity more often than the overall American population in a variety of ways. Traditional measures of religious participation, such as church membership, frequency of prayers, and religious self-identification, indicate that Black Americans have significantly higher levels of religious participation than White Americans. Nearly eight out of ten (79%) of Blacks say religion is very important in their lives compared to 56% among the general population. Blacks attend church services more frequently than Whites. More than half of them (53%) attend church once a week compared to only 39% for Whites (Sahgal, 2009). This finding was consistent among all Blacks in the United States, irrespective of their ethnicity and origin (Taylor et al, 2007).

In the 1980s and 1990s, a series of cross sectional and longitudinal studies, that focused on the link between religious involvement and psychological well-being, suggested that religious expressions lead to several health promoting behaviors. The studies proposed that active participation in religious organization, such as regular church attendance, builds social support networks that offer a variety of health promoting benefits, including reducing the risk of depressive disorders and increasing psychological well-being. Frequent and regular interactions with individuals who share similar values foster a sense of community in which members can feel cared for and valued. Support among church attendees boosts morale through confiding and companionship, and reduces the stress of uncertainty through messages of hope (Ellison & Levin, 1998). Religious practices such as prayer and meditation serve as

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valuable coping mechanisms in dealing with health problems. They provide solace and a feeling of secondary control through the divine. Consequently, they increase confidence in overcoming difficulties and optimism about achieving desired health outcome (Ellison & Levin 1998).

The National Institute of Health (NIH) research on the religion-health connection in the Black population found that church-based social support shielded Black women from stress-related illnesses and generated a strong positive effect on the well being of the Black population in general. When faced with the uncertainties about beating disease, avoiding recurrence, and losing the ability to function, many of Black patients turn to faith for assurance to regain health and resume a normal, healthy life. Faith also provides patients with answers about the meaning of life and death so they gain strength and positive outlook to life (Holt et al, 2013, Henderson et al, 2003). Other studies found that religious attendance lowered Blacks' mortality risk by 36%. Similarly, the National Center for Health Statistics (NCHS) complied data on more than 20,000 Black adults over an eight-year period and found that the estimated life expectancy for regular church goers was fourteen years longer (60.1) than non church goers (46.4) (Levin et al 2005).

Literature on Black religiosity cites church membership as another aspect of religion that increase Blacks' positive attitude the most. Black churches play a central role in building strong communities with a sense of collective group identity and interest. In doing so, Black churches promote a general positive feeling and a sense of strengths among their congregation members. Members of Black churches report that the church

helps them live their lives feeling good and happy while it removes their sadness and depression (Taylor et al, 1987, (Levin et al 2005).

Most of the literature on the religion cancer connection among the Black population focuses on religion's effects on cultural attributes in general. This study will compare the various dimensions of cultural attributes between Black and White survivors of early stage cancers. The study[·] will also analyze how religion influences Black survivors cultural attributes.

II. INTERVIEW SUMMARIES AND COMPARISONS

I interviewed four breast cancer survivors, four colorectal cancer survivors, two bladder cancer survivors, two endometrial cancer survivors, two brain cancer survivors, and sixteen prostate cancer survivors. Interviews with study participants lasted between 20 and 60 minutes during which Black and White participants, with comparable cancer types and stages, and comparable socioeconomic status, spoke about their experiences. The nature of the open-ended questions allowed participants to speak freely about the topic. Consequently, some participants took more time to delve into the details of their experiences than others.

1. *Breast Cancer*

I interviewed four breast cancer survivors, between the ages of 45 and 75. Two of the survivors were Black and two were White. All four participants have been

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[·] The study was approved by the Institutional Review Board. IRB #PRO00015100

receiving routine screening, and all had family history of cancer. Yet, all were shocked to learn about their diagnoses. The four participants initially considered breast cancer to be a death sentence, but changed their views after their successful treatments.

The two younger participants (age 45-49), one Black and one White, were concerned about their body image. They discussed their options with their spouses to ensure that their choice of treatment would not affect their relations with their husbands. The Black participant seemed more concerned about her body image than the White participant, and was more reluctant to tell her family about her diagnosis. Both younger participants opted for the more conservative treatment options of lumpectomies. Both stated that prior to their diagnoses, they took their health for granted and were too busy with their daily routines. The two women stated that their experience with cancer forced them to slow down and pay more attention to their health.

In contrast, the two older participants (age 70-75), one Black and one White, who were both retired and widowed, had no such concerns. They had been seeing their doctors regularly to deal with other health issues. Both showed firm resolve to eradicate their cancers, and were more inclined to make the decision for total mastectomies, though the White participant asked for a more radical option than the Black one. All four women stated that they make a point in encouraging other women, especially family members to get routine breast cancer screening.

2. *Colorectal Cancer*

Four colorectal cancer survivors joined the study, two Black and two White women, aged 50-72. All four survivors were surprised to learn about their diagnoses,

except for the older White participant, who had a strong family history of colorectal cancer and had been anticipating to be diagnosed with it for some time.

Both older participants (72 & 71), one Black and one White, had a less emotional and a more pragmatic approach to their diagnoses than the young participants. Unlike the White participant, who had been getting regular screenings, the Black participant had not known about cancer preventive screenings. During the course of treatment, the White participant demonstrated more courage than her Black counterpart. Her initial response to her diagnosis was "*let's get it out of there.*" The participant described her reaction as "*not panicky or anything.*" She confronted her diagnosis fearlessly and kept a positive outlook. She was also very grateful for catching her diagnosis early, noting that if one catches it early, cancer is easy to manage. She did not report having any difficulties during treatment, nor did she report needing any support.

The Black participant was extremely scared to hear the "*bad news*" initially. However, she was quick to overcome her fears, and started looking for a surgeon to remove her tumor. Although she had the same course of treatment as the White participant, the Black participant reported facing physical and mental difficulties during the course of treatment. She reported becoming so weak that her doctors stopped her radiation treatment for a few weeks until she regained some strength. The participant received enough support from her daughter and friends to alleviate treatment difficulties. She joked about her daughter's friends adopting her, visiting her on regular basis, and taking her places with them. Like the White participant, she was thankful for the

treatment. She stated that she gets up every morning and thanks the lord for being alive while enjoying the view outside her window.

For both younger participants, the cancer diagnosis was incidental to another problem. Recalling her account of her cancer experience when she lived in New Jersey, the White participant said that doctors discovered her cancer as they examined her colon in search of an answer to an unexplained rectal hemorrhage. She was admitted to the hospital several weeks prior to treat an infection resulting from a tic bite. Despite losing several family members, including her father, to cancer the participant had not been receiving routine screening due to the lack of health insurance. Her compound ordeal of the tic bite infection, the cancer diagnosis, and the recent death of her father, took a toll on her mental well-being to the point that she needed psychiatric counseling throughout her cancer treatment.

Unlike the White participant, the Black participant reported receiving routine colorectal cancer screening. Her diagnosis was incidental to an episode of chest pain, which resolved on its own within a week. As a precautionary measure, her doctor insisted on performing a colonoscopy. The colonoscopy revealed an early cancer formation, which made the participant extremely pessimistic. She feared losing her autonomy and wasting away in a similar fashion that she had witnessed close family members do after late stage diagnoses of different cancers. Her husband countered her pessimism with constant assurances about her prognosis.

Both younger participants stressed the importance of family support during treatment. The Black participant asserted that her husband played a critical role in her

healing through his support. The White participant cited the need for family support as the reason for moving to Florida after her recovery. Her experience in going through cancer without enough family support propelled her to move closer to family so she does not go through a similar experience in the future.

3. *Bladder Cancer*

   Of the two men with stage II bladder cancer history who participated in the study, the White participant appeared more shocked to learn about his diagnosis than the Black participant. He stated that he had not had a chance to research his condition because his doctor quickly referred him to a specialist who surgically removed the cancer within a week. The participant reported receiving support from his family, and indicated that he has been taking better care of his health since then.

   The Black participant also stressed that his cancer motivated him to make healthy life style changes and strictly follow his doctor's advice. He invoked his religious beliefs as the reason why he followed the doctor's advice because believed that God gave the doctor the knowledge to treat him. With all of his family members living in other states, the participant had no family members in the area to help him during treatment, but that did not seem to bring down his positive outlook and hope for recovery.

4. *Brain cancer*

   Two young women, one Black and one White, with history of brain cancer participated in the study. The Black participant had a much more dramatic experience

because her tumor was more aggressive in nature than the White participant's. Consequently, the Black participant was more scared of death at the time of diagnosis. However, the physician's quick response to send her to a reputable facility to remove the tumor eased her fears and boosted her trust level with her doctor. The participant also stated that her faith in God put her at ease with the impending brain surgery. The participant received a lot of support from what she referred to as "*a lot of praying family*".

Conversely, the White participant stated the she received support only from her mother and brother. The nature of their support differed from the support that the Black participant received in that it consisted of encouragement rather than prayers. Her mother always made sure she kept her appointments and her brother, who is a cancer survivor himself, regularly assured her that her condition would pass and that she would be cured. The slow-growing nature of her tumor gave her enough time to independently research her condition. The participant expressed deep trust and satisfaction with her doctor through statements like "*and reading up on it I found out that Dr…. did exactly what needs to be done.*" She also stated that he always made her feel secure.

5. *Endometrial Cancer*

Two endometrial cancer survivors, one Black and one White (ages 40-49), participated in this study. Both had difficulty accepting their diagnoses and both were upset about the loss of the ability to have children as a result of the cancer. However, while the Black participant was optimistic because she (erroneously) believed that removing her tumor was going to leave her cancer free for the rest of her life, the White

survivor feared her diagnosis was going to end her life. She demonstrated optimism after being declared cancer free. Both participants have been actively involved in their health care since finishing treatment.

The two participants were satisfied with their physicians. The Black participant consulted with a well-known cancer Center for a second opinion while the White participant consulted with her sister's gynecologist. In both cases, the second opinions concurred with the treatment plans proposed by the original providers. The Black participant was surrounded by a large family who prayed for her healing and offered her a lot of support. The participant's faith eased her depression and helped with her the decision to undergo surgery.

In contrast, the White Participant received less support because she had only a few friends in the area aside from her sister. She commended her sister for being by her side whenever she needed help. In contrast to the Black participant, the White participant rejected the notion of praying for healing and declined a friend's invitation to go to church.

6. *Prostate Cancer*

Prostate cancer participants made up half of the total number of study participants. A total of sixteen prostate cancer survivors, eight Black and eight White, with ages ranging between 50 and 82 years joined the study. Participants younger than 60 years of age were more likely to be surprised by their diagnoses, and more likely to be fearful for their lives. Conversely, participants over 60 were more accepting of their

diagnoses and less fearful of their lives. In addition, Black participants were more likely to voice surprise about their diagnoses.

All participants agreed that prostate cancer is deadly only if it is not treated early. Participants from both racial groups with a family history of prostate cancer, and older participants, predicted that they would be diagnosed with prostate cancer at some point in their lives. A former military officer stated that he and his golf friends consider prostate cancer as a badge of merit. Another participant speculated that if a man lives long enough he will get it and predicted that most men in any given funeral home have prostate cancer. A Black participant said jokingly that he "*kept playing hide and seek*" with the cancer until he found it.

White participants expressed a high level of trust in their physicians with statements like "*I have faith in doctors*" and "*I just go there and do what they tell me to do*", and all adhered with their physicians' treatment plans without questioning them. Conversely, three of the eight Black prostate cancer participants (37.5%) were skeptical about their treatment plans despite going along with them and getting good results. Two of the three skeptics voiced their distrust of the medical profession because of its historical racial practices against Black patients, but still trusted their own physicians. The third skeptic voiced mistrust of even his own physician.

Participants in both groups received support from family and friends. Support came in the form of empathy, sharing of experiences, and advice. Black participants were more likely to ask for support from church congregation. White participants, on the other hand, did not report speaking about their diagnoses in front of their congregations.

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IV. Interview Analysis

I used the Constant Comparative Method (CCM) to analyze interview transcripts. CCM is a process in which newly collected data is compared with previously collected data by way of coding. For this research I used Selective Coding to extract participant statements relating to dimensions of the four cultural attributes. Selective Coding refers to selecting statements that relate to preset categories which had been derived from old data (Kolb, 2012). To clarify: I began the analysis by reading interview transcripts (new data) in search of statements relating to the various dimensions of fatalism, physician trust, social support, and self efficacy (old data). I coded statements relating each dimension with a different color. Given the importance of religion in the Black population's lives, I also used selective coding to extract all remaining participants' references to religion. In the last step of the analysis, I compared and contrasted Black and White participants' statements and arranged them in tables 1 through 6. Then I wrote down my observations and conclusions.

V. The Religious-Secular Divide between the two Racial Groups

Interview analysis shows that Black participants were more inclined to frame their cancer experiences in a religious context than White participants. They invoked religion and God 47 times more than White participants did. One participant considered God to be the driving force behind her decision to seek treatment, and the source of confidence

that she will be cured. She enthusiastically noted: "*if it wasn't for God, I would not be clear with it. It is all about God in my book*" (Brain I).

Another Black participant recounted how he confronted his diagnosis fearlessly saying: "*my faith teaches me that if God chose cancer for me then he can heal me. God's will is bigger and better than my will*" (Prostate I). The participant's faith made him surrender to God's will and accept the diagnosis. It also gave him confidence that God will heal him from the cancer just like he willed it for him.

In the same vain, a third Black participant's Christian faith propelled him to leave it to God to heal him from cancer. He responded to his diagnosis by asking God to heal him through the work of his doctor: "*Well lord, whatever you can do to make the Dr… hand cure me, I appreciate it.*" He stated that both him and his family left the matter in the hands of God. "*whatever happens to me, I'll just let the man* [pointing upwards*] handle it.*" (Prostate I). The participant had such a firm belief in God's ability to cure cancer that he urged every cancer patient to rely on God for healing: "*I would tell them that I had cancer, God cured me from it and he can do the same for you. Just pray.*"

Prayer was the means through which Black participants communicated with God their submission to his will, and the means to ask him for healing. A breast cancer participant asserted that she keeps a relation with God through prayer: "*I prayed…I mean I am Christian and I have a relationship with the lord and I know he is there.*" A prostate cancer participant voiced his confidence that God will heal him through prayer: "*I always believed in the medication that … prayer to the lord that I will be delivered. So, I believed that I will be alright.*" A colon cancer participant used prayer to consult with

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God before taking any step for treatment: "*I thought about going to Tampa, and he told us that they can do the same here as in Tampa. I prayed about it so we went to the hospital here*". She added: "*for advice, It was just my husband and I and I prayed about it*".

White participants, on the other hand framed their cancer experience in a secular context. Instead of referring to the cancer diagnosis as something that *God chooses*, they referred to it as something that *happens* as one participant said "*If it was going to happen it was going to happen.*" (Prostate I). Further, instead of deferring to God's will for healing, as Black participants did, they considered cancer a problem that *they* needed to address. This secular frame was consistent even among White participants who identified themselves as good Christians or as having a strong faith in God.

> "*Everybody knows and hopes never to get it, but when it comes you have to accept it and see what you can do, correct the problem, or forget about it and let it takes its course.*" (Prostate I).

> "*Obviously it is something that had to be taken care of.*" (Breast II)

> "*if I am going to have it, I will get it out 100%*" (Prostate I)

The difference in the frame reflects Black participants' higher level of religious coping during stressful times. Blacks are more likely to resort to prayer, and look to God for support strength and guidance in stressful situations, such as a cancer experience than Whites (Chatters et al, 2008). Table 6 provides full account of Black and White participants' references to religion.

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1. *Fatalism*

Cancer fatalism, a belief that death is inevitable when a cancer diagnosis is present, has been a major barrier to cancer screening and treatment among the Black population. Barbara Powe's fatalism scale, which I used in the quantitative portion in this study, identifies three dimensions for fatalism. The first dimension, predetermination of the cancer diagnosis and death, measured participants' beliefs about the certainty of being diagnosed with cancer and dying from it. The second dimension, luck, measured participants' perception of the role luck plays in a cancer diagnosis. The third dimension, pessimism, measures participants' outlook about getting cancer and dying from it (Powe & Finnie, 2003).

Powe (1997) notes that fatalism can be the product of religiosity when it constitutes a submission of the human spirit to God in a way that destroys personality, hope, and ultimately life itself. Religious fatalistic individuals express their perception of cancer as "*God's will*" and "*the way God meant for me to die*". This perception instills a feeling of hopelessness, helplessness, and inevitable death. Fatalism leads to lower screening and treatments and higher death rates (Powe, 1997). Studies conducted on randomized population samples found that Blacks persistently have higher levels of fatalism than Whites (Mayo et al, 2001; Miles et al, 2008).

Close examination of Black participants' behavior and statements on cancer diagnosis and death cast doubt on the validity of Powe and Finnie fatalism instrument (Table 6). Black participants made twice as many references to predetermination than White participants (4:2, which translates to a confidence interval of ± 9.92 for Black and

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± 7.08 for White participants at a 95% confidence level) (McCallum Layton, 2016), but their acceptance did not translate to belief in the inevitability of death. One Black participant summed up this mindset by saying that if God willed him to die of cancer then he was willing to die, but not without a fight. Almost all participants, Black and White, stated, in various ways, that cancer is not a death sentence unless it goes untreated. Further, participants in both groups were optimists rather than pessimists about being healed from cancer. One participant affirmed: "*I had a positive outlook that I was going to be healed. I just had to go through the process of the mastectomy.*"(Breast II, Black). For this participant, healing from cancer was a matter of undergoing a mastectomy, which she referred to as a "process".

Another Black participant expressed his lack of fatalism by stating: '*I go about and teach people about faith and about healing, and I thought if I preach it then I have to live it. So I did not let it bother me.*" (Prostate I). The statement from this participant reflects his firm belief that he would be healed from cancer rather than die from it. He sounded confident of his control over the cancer diagnosis, which he dismissed as nuisance that he would not allow to bother him "*I did not let it bother me.*"

A third participant, who served as a preacher, considered the combination of medication and prayer as necessary factors for healing: "*I always believed in the medication that the medical doctor gave and prayer to the lord that I will be delivered. So, I believed that I will be alright.*" (Prostate I). By using the expression "I always believed…", this preacher participant pitted the permanent state of his belief in the

combined forces of medication and prayer against the temporary state of his diagnosis, and was confident that the former would overcome the latter.

These statements underscore participants' low levels of fatalism and conviction that they will be healed once they finished treatment. Further, Black participants who expected to get cancer did so, not because of luck, but because they knew that they were genetically predisposed to it since they saw it running in their families as this participant put it: "*I was expecting it. It runs through my family. My father, my brother, I expected it.*" (Prostate I). Another participant began routine check-ups when he saw other family members get cancer and realized the possibility of him getting it as well

> "*My family has the tendency that when they see somebody come down with something they analyze things and they see the possibility of them getting it so they take preventative measures and act appropriately…. In my case it was a matter of me doing the regular check-ups.*"
> (Prostate I)

A third Black participant's statement indicated that he was anticipating his cancer since he learned about his brother's diagnosis. "*I called my brother who had the cancer and told him: I got it too now. I am going to have to deal with it and take care of it.*" (Prostate I). For the participant, it was inevitable that his doctor would find tumor in his prostate. Therefore, he had his treatment plan ready even before his diagnosis.

Some participants tried to explain the fatalistic attitudes of Black cancer patients, especially older Black men. A participant with a history of prostate cancer explained Black men's reasoning for avoiding cancer screening:

> "*You will be surprised about other men they do not want to know. You tell them to go check their prostate and they say*

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> *I do not want to know about it. They are afraid of going to the doctor*
> *because they are afraid of the doctor telling them they have it.*
> *It is crazy but that is the mentality"*   (Prostate I)

The participant derided older men's avoidance of potentially life-saving screening. He considered it illogical that those men fear hearing about cancer so much that they choose to risk their lives rather than facing their diagnoses and treating them.

Another participant explained the old men's mentality, which the previous participant lamented as "crazy", using the story of a friend who died from prostate cancer as an example:

> "*A lot of African-American men are quiet about it and would not*
> *go to the doctor for it. They do not go for the treatment. They*
> *do not want anybody to know about it, just like my friend who*
> *did not want tell anybody…... Most men would not talk openly*
> *They do not say anything to anybody. They do not tell their*
> *wives. My friend did not tell even his wife. Their pride.*
> *I am too proud to tell anybody that I have a problem*
> *so I hide my problem and I do not tell anybody, especially when*
> *dealing with sexual organs. They are macho and strong.*"

The participant attributed the death of his friend, and so many other Black men with prostate cancer, to the refusal to discuss prostate cancer with anybody. Treating prostate cancer requires patients to discuss their diagnoses and treatment plans with loved ones who will care for them patient during treatment. According to the participant, many Black men are too proud to discuss their illnesses. They fear that such discussion would compromise their manhood. Their fear is exacerbated when the illness has to do with their sexual organs.

Older Black men's reservation against prostate cancer screening and treatment is due to hegemonic masculinity rather fatalism. Hegemonic masculinity is a western

cultural male gender construct that is associated with being White, heterosexual, and middle class. The construct carries masculine stereotypes of assertiveness, dominance, physical strength and emotional restraint (Evans et al, 2011). Black men have historically been excluded from the hegemonic masculinity cultural construct. They have not been able to attain dominance and middle class status because of slavery, Jim Crow laws, and high unemployment and incarceration rates. However, they still embrace the hegemonic masculinity construct because it gives them the benefit of dominance over women and homosexual men. Black men compensate for their compromised hegemonic masculinity through sustained sexual activity (Waverly, 2009). The Black men that the above participants mentioned understand very well that their masculinity has been compromised. Therefore, they resist any knowledge about a diagnosis that further would compromise their masculinity by preventing them from expressing it.

Stoicism is another contributing factor to Black men's reservation against prostate cancer screening. Stoicism is an ancient Roman philosophy founded by Zeno of Citium around 300 B.C., which believed that virtue consisted of a will exercised in accordance with nature and uninfluenced by all mundane desires. Stoicism called for self-reliance and suppressing and denying all forms of emotions, including pain and fear (Wagstaff & Rowledge, 2010). Older Black men's stoicism manifests in hiding their cancer pain from everybody, including their doctors and spouses. Self reliance manifests in maintaining daily activities without seeking any help. The distinction between stoicism and fatalism lays in the human agency. Fatalism diminishes the

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human agency by placing the locus of control in an exterior factor, like God. Stoicism, on the other hand, maintains the human agency, but aligns it with an exterior factor.

One Black participant dismissed fatalism as a hindrance to treatment as extinct, and considered the lack of health insurance as the only remaining hindrance to treatment *"the only reason why people would not get treatment is because of insurance. Only people who do not have insurance they put it off and put it off until they have to go because their life depends on it"* (Prostate I).

White participants also demonstrated low levels of fatalism. Those who anticipated to be diagnosed with cancer did so, not because of luck. Rather, it was because they were genetically prone to getting cancer as they could tell from on their family history. A participant with a strong family history of colon cancer noted: "*My sister had colon cancer and I am the youngest of 6 children and one of my brothers, he passed since then, had been watching it because they have always had the polyps, so it wasn't a real shocker*". Another participant said: "*Because both of my parents had it I assumed that I was going to get something. My father died from prostate and my mother died from breast cance*r (Colon, I). Prostate cancer participants knew their chances of getting cancer increased with age. One participant said that as he researched it, he found that if a man lives long enough he will get prostate cancer. Several older participants stated that they were not worried because they knew prostate cancer was common in their age.

Most White participants were optimistic, rather than pessimistic about their future. They stated that they plan to live normal lives " *I have always been an optimist… you*

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have to be thankful for what you have, and I am" (Breast II). One participant was optimistic about the advances in cancer treatment technology that provided her with hope about beating cancer (Breast II). A colon cancer survivor concurred and shared her optimism by stating: "*They are always coming up with new cures.*" Participants appreciated treatment advances because such advances allowed them to live longer and healthier lives: "…*So me living longer than my father did… the medicine helps you live longer, which they do today. So we live longer and we have the benefits of technology to make that happen in medicine.*" (ProstateI).

The religious-secular difference between Black and White participants' statements was evident in the predetermination and optimism factors mentioned above. Black participants expressed their belief in predetermination with statements like *"I just had faith in Lord if he wanted me to have cancer, then he can heal it"* (Postate I), and "*there is nothing that I can do about it. I believe in God and I leave it God's hands*" (bladder II). White participants articulated their belief in predetermination is statements like "*If it was going to happen it was going to happen*" (Prostate I), and "*if I am going to have it, I will get it out*" (Bladder II). Similarly, when Black participants talked about their optimism about their prognoses, they made statements like "*I survived it with God's will*" (prostate I), and "*lord I have too much to live for it and I know this is not going to take me out*" (Breast II). White participants, on the other hands expressed their optimism with statements like "*Quite frankly, I am sure that I would not be as good as I do today if I did not get the treatment*" (Prostate I) and "*there is hope and it will get better*" (Breast II).

Both Black and White participants initially feared death at the time of diagnosis but

changed their views after treatments. Table (3) shows examples of the similarities in the attitudes between the two groups. Participants in both groups realized how much treatment improved the survival odds for patients with even more advanced stages than they were. Finally, all the participants agreed that cancer is deadly only if is caught late. This conclusion confirms the quantitative analysis result that shows Black participants do not have a higher level of fatalism than White participants.

2. *Physician Trust*

The Physician Trust Scale focuses on three dimensions: technical competency, care for patient needs, and honesty in delivering medical advice. Technical competency measures patients' perceptions of the physicians' technical expertise and whether they keep up to date with advances in medical knowledge. Care for patient needs gauges patients' perceptions of whether their doctors view them as persons rather than sheer cancer cases, and treat each one of them with a holistic perspective. Honesty in delivering medical advice assesses whether patients believe their doctors tell them the truth about their diagnoses and treatment, and whether they withhold information from them if they make a mistake in their treatment (Freburger et al, 2003). Table 7 lists participants' references to these dimensions showing little difference in the number of references between the two racial groups. Black participants made seven references and White participants made eight references to physician trust.

Black Participants' quotes reveal two sources of trust in physicians' technical competence: The first source was physicians' reputations for successfully treating other

patients with similar conditions. As a participant with bladder cancer said: "*Dr. H., his reputation is crown* [sic] *so I felt comfortable with him. My primary care doctor told me that Dr. H. was the best doctor.* " (Bladder). The second source was participants' findings that physicians' management matched the best practices cited in the literature. "*I read that people over a certain age must have colon cancer screening. I went to my doctor and told her that I never had one so immediately she called the guy who does them"* (Colon II).

Black Participants trusted their physicians on the "patient need" dimension when the physicians sought treatment courses that suited patients best. In some cases, seeking the best treatment option meant simply choosing a treatment that the patient is comfortable with, such as a non-surgical option. Many Black patients avoid cancer surgery because they fear that the surgical intervention will spread the cancer (Margolis et al, 2003).

> "*I told him that I prefer radiation. He said I will send you*
> *to the best facility for radiation and he did. My family*
> *is against cutting so they supported my decision for radiation*"
> (Prostate I, Black)

In other cases, it meant suspending treatment when the patient could not tolerate it
> "*I was so sick. I could not walk by myself I needed help.*
> *... When I complained to the people in chemo they*
> *said it was the radiation and when I complained to*
> *people in radiation they said it was the chemo until*
> *one day after the chemo and radiation I was feeling*
> *so bad I had to be held up. The technician called*
> *the oncologist who examined me and said you have to*
> *stop this right now. He called the chemo and radiation and*
> *told them to stop. So I stopped for two weeks and I felt ok*
> *then I resumed.*" (Colon, II Black)

Catering to patient needs in other cases meant being diligent about finding the problem

and treating it, even when the patient was not convinced that treatment was needed:

> *"He did biopsy and said I can't find it, but it is there.*
> *It is there. We need to do another biopsy. He went*
> *to the hospital and did it. He said here it is and showed*
> *it to me. It is just started. It's stage one. He gave me options."*
> (prostate I, Black)

> *"I am glad that he said what he said because I tried talking*
> *out of it... And Dr. A. was saying let's get this test done,*
> *let's get this test done, so I am glad that I agreed with him*
> *and had the test done"* (Colon, I, Black)

White participants shared similar observations about their physicians' catering to

their needs. One participant noted how her doctor catered to her need by changing the

timing of the medication to accommodate her lifestyle

> *"I was sick like a dog. I was throwing up a lot. The*
> *odd thing is that he (the PA) kept saying that tomaxafin*
> *does not do this to you ….. The oncologist then told me*
> *to take my tomaxafin at night before going to bed…. not*
> *have to worry about getting sick in public and it can do its*
> *dirty work while you are sleeping. It has been a year and*
> *a half since I vomited."* (Breast II, White)

Suspending treatment was another way of catering to patient needs for this prostate
cancer survivor

> *"Four years after the seed implant it (*the cancer*) started*
> *to come back so I have been getting Lupron shots. Six months*
> *ago, I told Dr. H., I won't take the shot anymore. I*
> *want to see what goes on."*

Another participant was pleased with the doctor's diligence with the treatment.

> *"Fortunately, in my case, my doctor was on top of things.*
> *If it wasn't for her, the stubborn person I am, I would have*
> *not gotten treatment."* (Prostate I, White)

Participants in both racial groups referred to "honesty in medical advice" more often than the previous two dimensions, which suggests that honesty in delivering medical advice is the most important dimension for patients. Both Black and White participants expressed their expectations about honesty to their physicians, and found their physicians to be honest through engaging in discussions with the physicians, asking questions about their diagnoses and treatment options, and through conducting independent research about those options. Some Black participants made the following statements:

> "The PSA came high and the cancer was growing fast…
> *I got in the habit of research. I researched the cancer issue.*
> *I had the surgery to remove the prostate." (Prostate I, Black)*

> "*I asked him (the doctor) if he was sure and he said*
> *yes and said the test showed that 99% I had cancer*
> *and after he told me that he told me how he can treat*
> *it*". (Prostate I, Black)

White participants made similar statements

> "*a doctor… who would explain everything*
> *so you knew, and reading up on it I found out that*
> *He did exactly what needs to be done."* (Brain, I, White)

> "*According to ….articles that I read…*
> *if a man lives long enough, he will develop prostate*
> *cancer*" (Prostate I).

The religious-secular difference in physician trust manifested in Black participants' view of their physicians. Black participants who trusted their doctors did so because they viewed them as a means through which God healed their cancers. The bladder cancer survivor considered his doctor's medical knowledge as God-given: *"God will give the doctor the knowledge of what to do."* Similarly, a colorectal cancer

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participant trusted her doctor because she believed that it is God that does all the healing through the doctor, and the doctor serves only as the means through which God works. *"I know that God does things and he does it all through doctors."* A prostate cancer survivor concurred but added that God gave the doctor medical knowledge by sending him to medical school. *"Lord, it is in your hands to let the doctor cure me….God gave him the knowledge and he went to med school."*

White participants, in contrast, did not make any connection between God and their doctors like Black participants did. However, they demonstrated a higher level of physician trust in that none of the White participants questioned their diagnoses and their physicians' treatment plans whereas three of the fifteen Black participants, (20 percent), were skeptical about the profession's handling of cancer, despite being successfully treated.

The first skeptic was in complete denial of his diagnosis. He denied that he had prostate cancer stating that it has not appeared in his family in the last one hundred years, and that he lives a healthy lifestyle that is not conducive to cancer formation. The participant, who had his prostate removed and has been having follow-up testing for the last six months, said he underwent treatment out of precaution only *"I still do not believe I have cancer. Dr…. has his opinion and I have mine."* Interestingly, the participant advised future cancer patients to defer treatment decisions to their doctors. His message to them was "*Get treatment if you need. Do no let it metastasize. If they are young, get the prostate removed. Leave it the professionals.*"

The skeptic exhibited a stoic attitude when stressed his ability to rely on himself

and suppress all emotions including pain as he did when dealing with a surgical

procedure earlier in his life:

> "Before, I had a procedure appendectomy I was
> exercising regularly and I had the procedure on
> Monday. By the next Saturday I was working on
> my pool with my stitches…On the third day I
> told the visiting nurse not to come and to take
> me off of her list I remained independent and
> by the next Monday. I had no pain and no aches."

The second skeptic did not have faith in the medical profession because of the

latter's history of discrimination against Black patients. He placed some blame for the

lack of screening and treatment on the medical profession by alleging that physicians

mislead Black prostate cancer patients. The skeptic argued that physicians downplayed

the danger of untreated prostate cancer when they told their Black patients not to treat

slow growing tumors:

> "Doctors were telling patients that they did not have to get treated
> for cancer if the cancer was slow growing, and they could just
> watch it, because men were very apprehensive about losing
> their sexual abilities this that and the other. So in order to
> please those men, doctors were saying if you have a slow
> moving cancer leave it there until you have to take it out
> and a lot of men were dying because of that."

The skeptic was referring to an Active Surveillance approach in dealing with prostate

cancer. Active Surveillance means closely monitoring the growth speed of a prostate

cancer through frequent testing of PSA levels. Doctors use the Active Surveillance

approach with older patients when the risks of other, more aggressive, treatment

options outweigh their benefits (Ratini, 2015). While the medical professions'

discriminatory practices against Black patients are well documented, the skeptic's

argument does not hold. It does not tell if Black patients actually checked the growth rate of their tumors to determine a treatment plans.

The skeptic grouped the medical profession with insurance companies under the category of "medical industry." He accused the insurance companies of ensuring that individuals do not live long in order to minimize their cost on medical care and criticized physicians for not volunteering advice for fear of lawsuits. "*The problem with having general health insurance, they do not want you to live for long. They do not want you use it and they ensure that you do not live long.*"

While the first two skeptics had no complaints about their own physicians, the third one feared that his doctor rushed him to surgery for profit motives.

> *"I think what the doctors do, I think sometimes they play the scare factor in there because they get paid for the surgery. I always had that in the back of my mind because the doctor kept telling me how small the cancer was, and kept telling me how concerned he was because my father died from it."*

He suspected that the doctor could have waited to assess the cancer danger and managed it through Active Surveillance rather than rushing him to surgery. The sixty-two year old participant, whose father died of prostate cancer, acknowledged that two different physicians advised him, on two different occasions, to undergo surgery because his tumor was fast-growing.

The participant's opinion is problematic for two reasons. First, the fact that he underwent the surgery suggests that he consented to it prior to being operated on. His current stand against the surgery indicates a change of heart after treatment. However, the participant did not give a justification for his change of heart about his successful

treatment. Second, his opinion stands out as an anomaly compared to other the opinions of other participants who were glad to have caught and treated their cancers early.

The quantitative analysis showed that Black and White participants did not have a significant difference in physician trust levels. However, the analysis did not measure the religious aspect of Black participants' trust in physicians. Assuming that the skeptics downgraded their doctors' "honesty in delivering medical advice" (the third dimension), the view of the Black participants who considered their doctors as God's agents for healing may have offset the negative impact of three skeptics by upgrading their doctors' " technical competency" (the first dimension) in the quantitative measure. The quantitative instrument might yield different results if it was applied on a less religious sample population.

3. *Social Support*

Social support refers to the assistance patients receive while dealing with a stressful event, such as a cancer diagnosis. There are three dimensions to social support: Cognitive, emotional, and material. Cognitive support means giving information that enables patients to make informed decisions about their treatment, such as providing cancer patients with information or advice on how to deal with treatment side effects. Emotional support means providing comfort and encouragement to patients. Material support is providing patients with tangible goods and services, such as

providing transportation to a caner patient to a radiation therapy session (Belgrave 1998, 69).

Table 8 shows some examples of the social support participants from both racial groups received. The support that participants experienced was fairly similar as the table exemplifies. Overall, Black participants reported receiving social support 32 times, compared to 23 times for White participants (confidence interval ±23.61 for Black participants and ± 21.3 for White participants at a confidence level of 95%) (McCallum Layton, 2016).

Material support was the least type of support received by both groups. Only one participant from each racial group reported receiving material support. Black participants received less cognitive support than White participants. Their families and friends supported their treatment decisions without offering additional information. Only prostate cancer participants were more likely than others to exchange information and discuss their diagnoses openly. In contrast, all White participants were open to discussing their conditions and exchange information.

> *"When I had mine, I started writing a daily e-mail*
> *to my children. Dad has this problem and this*
> *is what is happening today. Now, some of my*
> *friends found out about it and said can you send*
> *us emails about it also so I started sending my daily*
> *letter to my friends, and from there, I found 3 guys*
> *having to deal with the same thing that I was dealing*
> *with so I started sending them letters as well. I have*
> *not stopped writing that letter. Today, over 500 people*
> *receive that letter every month."* (Prostate, I, Black)

> "*It is not something that I try to hide….It is important*
> *for someone to go with you to the doctor. Because*
> *even if they may already know what is going they*

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> *still want to be with you. You still need someone to*
> *say let us go this way or let us get a cup of coffee*
> *or whatever.*" (Breast II, White)

> "*A friend of mine….She had every side effect….,*
> *she was having trouble eating and chewing, but I*
> *also urged her to stick with it.*" (Colon I, White)

> "*I talked to the guys I was working with. They are*
> *all retired military also, and we exchanged information.*"
> (Prostate I, White).

Emotional support included extended visits from children and other family members, providing participants with opportunities to express fears and concerns, and giving them assurance and hope.

> "*my son came when I went to have the surgery*
> *and stayed a couple of nights with me*" (Breast II, White)

> "*My daughter…wrote an affirmation and asked me to read*
> *it everyday. The affirmation states that I am alive*
> *and I will get better and that I am getting the best*
> *treatment out there.*" (Colorectal II, Black)

> "*My husband said we will get through this*
> *together, and I am here for you, listen, you*
> *want to be mad, you want to cry and whatever.*"
> (Endometrial I, Black)

> "My brother would tell me to hang in there and
> that it will pass." (Brain I, White)

Black participants who were more active in their churches received more social support from their congregations than White participants did. This finding is consistent with the research on Blacks' church involvement and social support. The church has historically been the second most important source of social support in the lives of Blacks after family (Taylor & Chatters, 1988). Many of the participants actively solicited

prayer, and some went as far as standing in front of their congregation and talking about their experiences with cancer.

> *"I spoke to my church, my pastor and he prayed for me.*
> *I called my Bishop in St Thomas and he said he will gather*
> *the Elders and pray for me." (Prostate I)*

> *"My family they prayed for me and visited me*
> *at the hospital." Pprostate I)*

> *"I have a lot of family and I lot of praying family….*
> *there was a lot of crying and praying." (Brain I)*

> *"I shared that with my pastor and the people at the*
> *church and then I also had the opportunity to share*
> *it with the congregation." (Breast II)*

> *"I stood up in front of everybody and said I have*
> *cancer. I have to leave and take care of it.*" (Prostate I)

Participants who spoke about their cancer experiences before their congregations did so for reasons other than soliciting social support. They spoke about it to encourage other congregation members to open up about cancer. The historical association between cancer and death made many Black folks hide their cancers until they died from it, which reinforced the cancer-death association in the minds of some Blacks. Participants hoped to encourage others to seek cancer treatment by encouraging them to talk about it.

> "*cancer was a dirty word and in the past people*
> *used to keep it to themselves.*" (Breast II)

> "*when I was in the hospital, I did not want visitors,*
> *but some close friends came, others were turned*
> *away.*"

> "*I talk to people about cancer and tell them about*
> *my cancer and how I survived it with God's will.*" (Prostate I)

"*And as a result of my sharing, I think it helped people that were later diagnosed.*" (Breast II)

4. Self-Efficacy

The term self-efficacy refers to the individual's perceived ability to perform a specified behavior. The concept of self-efficacy is grounded in social learning theory that focuses on the reciprocal interaction between perception and behavior. Individuals with greater perceived confidence with regard to a particular task are more likely to engage in achieving that task. For example, patients are more likely to ask their doctors questions about their conditions if they feel confident that they will get answers when they ask their doctors (Wolf et al, 2005).

Wolf et al (2005) developed a three-dimension instrument to test patients' self-efficacy when dealing with cancer as participants' statements exemplify. The first dimension is adjusting to the cancer diagnosis, which refers to the patient's attitude "*just look forward getting better and you will get bette*r" (Colon I, Black). The second dimension deals with initiating communications, which refers to seeking and communicating information "*ask for an opinion and find out exactly what is going on*" (Breast II, White). The third dimension is engaging in recommended health behaviors and making health decisions "*I made the decision to do what I did*" (Prostate I, Black). (Wolf et al, 2005). Overall, Black participants made a total of 163 statements relating to self-efficacy compared to 85 statements made by White participants. Table 9 highlights examples of such statements.

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The two participant groups reported the same number of references to the latter two dimensions. Most participants stated that they conducted Internet research about the disease and treatment options; and most discussed their options with their doctors. A few participants exchanged information about their conditions with their doctors and peers. All participants' statements relating to seeking information and making health decisions begin with "I" followed by and action verbs like "decided, chose, engage, talked, researched…", which reflects participants' taking initiative in their health care. The statements reflect participants' firm resolve not only to get rid of the cancer, but also to minimize the chance of its recurrence.

Participants in both groups expressed their positive attitudes in three ways. First they emphasized their resistance to the hardships associated with cancer. Their use of phrases like "*stay strong*", "*I felt very very confident*", and "*you need strength, happiness and normality*" show their steadfastness in fighting cancer and their confidence that they will get better. Many participants stressed the importance of living a normal life throughout the cancer treatment period "*You just keep doing it. One day at a time you just keep going through it.*" They warned against dwelling on their health problems or worrying about potentially adverse outcomes. A participant who survived prostate cancer gave this advice: "*If you start worrying about it and everything,….. It can aggravate it and make it worse. I would tell them live life everyday like you have always and whatever happens happens.*"

Second, surviving the cancer experience taught participants to better appreciate life: "*life is important…,we live longer and we have the benefits of technology to make*

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that happen in medicine". All participants stressed the need to appreciate each day and make the most out of their lives. This is exemplified through statements like "*I get up I enjoy the view… live one day at a time*". Participants also highlighted the importance of surrounding themselves with positive people to lift their spirits up when they felt down, such as when the breast cancer survivor said: "*surround yourself with positive people.*"

Finally, participants in both groups expressed positive attitude by being thankful for surviving cancer, albeit it different ways. Both groups expressed their gratitude for catching the cancer at an early stage when it can be easily treated. One survivor said "*I have been very fortunate*", and another stated "*you have to be grateful for what you have*". Gratitude for catching cancer early made them appreciate the importance of maintaining good health. Statements like "*I would not be as good as I do today if I did not get the treatment*", and "*I joined the Y, and I kept my routine. I still go to the gym, I still bike everyday, so it worked out for me. I stay healthy and let the process work*" serve as examples of such gratitude and emphasis on caring for their health.

Black participants added a religious dimension to the sense of gratitude, which increased their level of self-efficacy in comparison to White participants. Black participants expressed their gratitude with statements like " *I survived it, but with God's will*" and "*if it wasn't for God, I wouldn't be here.*" They prayed to God for healing, and trusted that he would give it to them. Using expressions like "*I just went in with God on my side…", "Trust God*", and "*prayer to the Lord that I will be delivered*", Black participants relied on their faith and prayer to boost their positive attitude "*pray for healing. Prayer is important*".

VI. Conclusion

During interviews with thirty Black and White cancer survivors, lasting 20-60 minutes each, 30 participants, 15 Black and 15 White answered semi-open questions about their experiences with cancer diagnoses and treatments. The purpose of the interviews was to compare experiences of Black and White participants with similar cancer diagnoses, and explore the effect of Black participants' religiosity on their levels of fatalism, physician trust, social support, and self-efficacy in comparison to White participants.

Black participants framed their discourse on their cancer experience in a religious context. They believed that God was the one who gives cancer and trust that he healed them from it. They viewed their physicians as God's agents for healing cancer. Conversely, White participants framed their experiences in a secular context. They stated that cancer can happen to anybody and that they have to get their treated.

Participants in both racial groups feared initially that their diagnoses would lead to death, but changed their mind after their successful treatments. All participants were thankful for catching their cancers early, and all have started taking steps to prevent recurrence. In addition, most participants now encourage close relatives to get routine cancer screening.

Examining the levels of fatalism by analyzing participants' statements on its three dimensions, predetermination, luck, and pessimism, showed that fatalism levels were equally low among participants in both racial groups. Participants in both groups believed in the predetermination, but were optimistic rather than pessimistic about

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healing from cancer. None of the participants considered the cancer diagnosis as a result of bad luck.

In discussing predetermination, the religious-secular difference between Black and White participants was evident in that Black participants considered their cancers to be predetermined by God. They expressed their acceptance of God's will to give them cancer. White participants, on the other hand, expressed their acceptance of their diagnoses without any reference to its cause. As for optimism, Black participants expressed their optimism about healing by stressing their trust that God healed them, while White participants expressed being optimistic about their healing because of medical and technological advances in cancer treatments.

There was no difference in physician trust levels between Black and White participants. They made equal numbers of references to the three dimensions of physician trust, which are technical competency, attention to patient needs, and honesty in delivering medical advice. However, while none of the White participants questioned their physicians' treatment plans, one Black participant feared his physician rushed him to surgery for profit motives and another denied having cancer and stated that his treatment was only precautionary. A third Black participant voiced his mistrust of the medical profession because of its historical treatment of Black patients. Black participants' religious view of physicians may have offset the negative effect of the three skeptics' statements. Their increased trust in physicians as God's agents and physicians' technical skills as God given may have counterbalanced the skeptics' views about their physicians' honesty in delivering medical.

Overall, Black participants reported receiving more social support than White participants. Social support is comprised of material, cognitive, and emotional support. Black participants received equal amounts of material and emotional support from friends and family but less cognitive support, than White participants. However, Black prostate cancer participants received equal amount of cognitive support as White participants did because they were more likely to exchange information with other prostate cancer survivors.

Emotional support that Black participants received from church congregations accounts for the higher level of emotional support and the overall higher level of social support. Some Black participants stood in front their congregations to share their experiences, and to encourage others to seek cancer treatment. The nature of emotional support also differed between Black and White participants. Participants from both groups received emotional support in the form of encouragement, but Black participants received prayers as an additional form of emotional support.

The three dimensions of self-efficacy, positive attitude, seeking information, and making decisions, determined participants' levels of that attribute. Participants in both groups expressed their positive attitudes in confronting the difficulties associated with the diagnoses and treatments with courage. They also expressed positive attitude by better appreciating their lives and by being thankful for diagnosing and treating their cancers at an early stage.

Black participants added a religious dimension of positive attitude by praying and thanking God for healing them. They cited the mental and physical benefits of prayer

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and the comfort they feel by trusting God with their health. The religious dimension increased Black participants' overall levels of self-efficacy.

The two racial groups had equal levels of the second and third dimensions of self-efficacy. Participants from both groups reported seeking information by conducting internet research about their diagnoses and best treatment practices. They also reported making decisions about treatment plans. Finally, all participants reported monitoring their health closely to detect any future recurrence.

This qualitative study offers a nuanced understanding of the similarities and differences in cultural attitudes between Black and White survivors relating to cancer diagnosis and treatment. The study addresses the role of religiosity in shaping the dimensions of fatalism, physician trust, social support and self-efficacy, among cancer survivors. Black participants' religiosity boosted their levels of physician trust with the belief that physicians are the means through which God heals. It bolstered their self-efficacy by teaching them to trust God and be grateful to him. Finally, Black participants' religiosity and involvement in church increased the levels of social support and expanded the sources of support they received while dealing with cancer.

This qualitative analysis has several limitations: first, the small size and nature of the self-selected, suburban population from which the sample was drawn may limit the applicability of findings to Black and White populations in suburban areas. Second, findings may not be applicable to populations from non-Christian faiths. Third, the study does not distinguish between participants' religious denominations. Rather, it assumes that all participants' denominations have the same effects on their cultural attitudes

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towards cancer. Finally, fatalism, physician trust levels, social support, and self-efficacy

levels may differ in cancer survivors with advanced stages of cancer. Future studies

may shed light on these populations.

Chapter Six

Conclusion

Introduction:

The present research fills a gap in the literature on Black Americans' cultural attitudes that may prevent them from seeking cancer treatment. The research consists of five chapters, with each chapter covering a specific aspect of the research. Chapter one explains the social and political environments in the American history that led to the cancer disparities among Black Americans. Chapter two discusses corrective measures aimed at closing these disparities. Chapter three explains the quantitative and qualitative methods used to conduct the research. Chapters four and five detail the quantitative and qualitative results of the research. This chapter summarizes the each of the five chapters and draws conclusions about the research findings. Then, it offers practical steps that public and private programs can take to mitigate the cultural barriers among Black Americans and uses the research limitations to suggest a future study on Black Americans cultural attitudes.

II. Research Summary:

Cancer afflicts Black Americans with a higher death rate due to delayed diagnosis and treatment. Chapter One explains how the disparities in cancer death

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rates emerged from the persistent racism that Black Americans have endured since their arrival to the United States. Black cancer patients often present with more advanced stages of the disease than White Americans, which limits their treatment options and shortens their life span (American Cancer Society, 2013). The chapter examines the three main patterns that of racism that Black Americans endured. Each pattern corresponded with the different social and political environments in the United States history. The first pattern marked the Slavery Era, between the mid seventeenth century and the Civil War (1865), when White plantation owners subjected Black slaves to vile living and working conditions that endangered slaves' health. Planters relied on White physicians to care for the sick slaves. Those physicians, in turn, subjected slaves to inhumane medical treatment techniques and dangerous experimentations (Byrd & Clayton, 2000).

The second pattern of racism began after the Reconstruction Era (1920s) and lasted until the second half of the twentieth century. It involved segregation and exclusion of Black Americans from the burgeoning American economy. Segregation policies translated to poor living and working conditions, dilapidated medical facilities with unqualified staff, and little access to medical training. The second pattern of racism also involved restricting the procreation and continuing the experimentation on Black Americans (Washington, 2006).

The third pattern of racism began with the election of Ronald Reagan in 1980 and continues until the time of the present research. This pattern is predicated on emphasizing the virtue of individual work, the assumption that Black Americans have an

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ample of opportunity for upward mobility, and that their poverty is a product of their own underachievement (Bonilla-Silva, 2006, 25). The pattern produced systemic racism and minimization of government health and welfare programs needed to correct previous injustices and lift the Black Americans from historical poverty. Consequently, Black Americans were confined to an environment of restricted employment and poor housing. Restricted employment prevented their access to high quality, employer-based health insurance coverage, and locked them in poor quality public insurance plans. Poor housing forced Black patients to rely on inner city and teaching hospitals where the pattern of abused continued as these patients were used as training subjects for medical students and surgical residents (Smedley et al, 2003 & Hoberman, 2011).

The three patterns of racism resulted in Black Americans being subjected to sustained discriminatory practices from the medical profession and the White population at large for over two hundred years. For Black American cancer patients, these discriminatory practices produced a set of distinct cultural attitudes that continue to hinder their ability to seek treatment. Fatalism, physician mistrust, low levels of social support and self-efficacy are common cultural attitudes that the literature cites (Powe & Finnie, 2003).

Fatalism is the belief that outcomes are predetermined and cannot be changed. A serious diagnosis, such as cancer, creates a sense of helplessness and the conviction of a death sentence. Fatalism prevents Black American men and women from seeking treatment for lung, breast, prostate, and colorectal cancers (Franklin et al, 2008, Peek et al, 2009; Blocker, 2003; Berry et al, 2003). Physician mistrust stems from

the long history of exploitation and experimentation by White physicians on Black patients. It creates a perception of differential diagnosis and treatment, and it makes Black patients less likely to seek, and adhere to, medical advice. Physician mistrust prevents Black prostate cancer patients, and Black breast cancer patients from following physicians' recommendation (Hammond, 2010).

Low levels of social support stem from the stigma associated with myths that surround a cancer diagnosis, such as the belief that cancer results from a genetic flaw, or that it is a punishment from God. These myths make it difficult for cancer patients to discuss their diagnoses with others, including physicians (Im, 2008). Self-efficacy is individuals' perception of their own ability to perform certain behaviors. For Black American cancer patients, low levels of self-efficacy reflect their perceived inability to overcome cancer as a result of the persistent discrimination that they have been subjected to. Low levels of self-efficacy prevent early screening of prostate cancer among Black American males (Wolf et al, 2004).

Chapter Two examines policies and programs aimed at improving Black Americans' overall health, and at closing the cancer disparities between Black and White Americans. These policies ensued during the Civil Rights Movement along with the push to expand health care coverage to large segments of the American population. The 1946 Hill-Burton Act expanded Black American patients' access to hospital services by providing hospitals with funds to build segregated wards for Black and White patients. Civil Rights advocates criticized the Act for cementing segregation and pushed for policies of integration. Their efforts culminated the 1965 Kerr-Mills Act, which

expanded the 1935 Social Security Act, to include Medicare, Medicaid, and Community Health Centers Programs (Morone et al, 2008, 334). These programs significantly increased Black Americans' access to high quality medical care and improved their overall health (Chabot 1971; Almond, 2003).

Despite these policies, cancer incidence and death rates persisted among the Black American population in comparison to the White American population. The American Cancer Society's 1990 pilot navigation program was the first attempt to understand the underlying causes of the cancer disparities. The program provided navigation services for a group of breast cancer patients in Harlem that included help with making appointments, providing transportation, and covering the cost of treatment. The pilot program significantly improved the group's cancer outcomes and life expectancy (Freeman & Rodriguez, 2011).

The impressive results of the American Cancer Society's pilot program spawned national interest in Patient Navigation Programs, and in closing the cancer disparities among Black Americans. To that end, several cancer centers around the country established Patient Navigation Programs (PNPs) aimed at closing cancer incidence and mortality gaps between Black and White Americans. Navigation Programs promote screening, early detection, treatment, and follow up throughout the patients' lives. These programs have succeeded in increasing screening rates, but not treatment rates, among Black American cancer patients (Freeman & Rodriguez, 2011). Failure to increase treatment rates prompted PNPs to examine their approach to the hindrances that Black cancer patients face. They found that Black American patients face three types of

barriers. Structural barriers deal with the lack of employment and adequate health care coverage; logistical barriers deal with transportation and child care; and cultural barriers deal with Black cancer patients' attitudes towards cancer diagnosis and treatment. PNPs found that navigators spend more time addressing structural and logistical barriers, but not cultural barriers that consist of fatalism, physician mistrust, low levels of social support and self-efficacy (Hendren, 2011).

Three of the four frequently cited cultural barriers that lead to treatment disparities among Black American cancer patients are rooted in their religious beliefs. Fatalism, the belief that health outcomes are predetermined by God, inhibits the patients' agency by placing the locus control in an exterior factor (Powe & Finnie, 2003). Lack of social support can result from stigmatizing cancer as a punishment for not living according to God's will (Im, 2008). Low self-efficacy is closely related to fatalism in that it inhibits patients' agency. It is also associated with pessimism, which is also a product of believing that cancer is a punishment from God (George et al, 2002). Addressing these cultural barriers warrants examining the role religion in affecting the health of Black Americans.

Most Black Americans embrace Christianity; and tend to be more passionate about their faith than White Americans (Saghal, 2009). Black Americans also tend to be more active in their church than their White counterparts. Their Christian faith plays a central role in their perception of health and in health-related decisions. Historically, Black Americans embraced faith healing through prayers, and the Black church has always played a big role in improving the lives of Black Americans (Ellison & Levin,

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1998). In terms of cancer, Black churches have held cancer prevention and screening programs; and served as a trusted source of information on cancer for their congregation members (Holt, 2013). The church's active involvement in promoting cancer prevention hints that not all Black Americans hold the cultural barriers that prevent them from seeking treatment. This raises the research question: Do Black Americans cultural beliefs hinder them from seeking cancer treatment?

Chapter Three details the methodology used for investigating the above question. The question assumes that if Black Americans have the same cultural beliefs as White Americans; they receive cancer treatment at the same rate as White Americans. Some scholars share this assumption believing that removing financial barriers is enough to eliminate cancer disparities (Brawley, 2008). Other scholars suggest that some disparities in cancer treatment persist because of cultural barriers that all Black Americans share. These scholars take a positivist reductionist approach by generalizing that all Black Americans share the same cultural attitudes that hinder their ability to seek timely treatment (Guildry, 2003).

The present research challenges such positivist reductionist worldview; and takes a postpositivist worldview that accepts multiple observations and alternative hypotheses. The research hypothesizes that Black Americans who receive adequate and timely cancer treatment have similar cultural attitudes towards cancer treatment as White Americans who receive cancer treatment. The present research also takes a pragmatic worldview that analyzes how Black cancer survivors who receive treatment overcome cultural barriers that hinder treatment.

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To implement the research, I conducted face-to-face interviews with a group of fifteen Black participants who received cancer treatment and a matching group of White participants, who also received cancer treatment. The interviews consisted of conducting survey questionnaires that tested the levels of the four cultural attitudes in question: fatalism, physician mistrust, social support, and self-efficacy. The interviews also included participants' narratives about their experiences with the cancer diagnosis and treatment.

Each cultural attitude is comprised of three dimensions: The dimensions of fatalism are the belief of predetermination of the cancer diagnosis and death, (bad) luck, and pessimism (Powe, 1995). Dimensions of physician trust are technical competency, care for patient needs, and honesty in delivering medical advice (Freburger, 2003). Dimensions of social support are cognitive, emotional and material support (Broadhead et al, 1988). Finally, dimensions of self-efficacy are adjusting to the cancer diagnosis, communicating with medical providers, and making health decisions (Wolf et al, 2005).

The research consists of quantitative and qualitative comparative analyses. Quantitative analysis provides the statistical significance of the differences in mean values of participants' scores for each cultural attitude. Qualitative analysis examines the cultural attitudes at the granular level, looking at how religion influences these attitudes. It also maximizes the research utility by providing suggestions for increasing cancer treatment rates among Black Americans.

Chapter Four explains the quantitative analysis of the present research. The analysis utilizes a two-tailed t-test to compare participants' mean scores on the survey

questionnaires (Lowery, 2015). t-test results reveal no statistical difference in the cultural attitudes between the two participant groups with 95% confidence. I conclude that Black and White cancer survivors who have been treated for cancer; and have similar socioeconomic status, have equal levels of cultural attitudes relating to cancer diagnosis and treatment.

Chapter Five discusses the qualitative analysis of the present research. It compares Black and White participants' narratives using the Constant Comparative Analysis method (Kolb, 2015). The analysis reveals the Black and White participants had equally low levels of fatalism and equal levels of physician trust. However, Black participants had slightly higher levels of social support and self-efficacy.

The qualitative analysis also revealed a stark difference in the way Black and White participants used religion to cope with cancer. Black participants framed their experiences with cancer in a religious context. They attributed both of their sickness and recovery to God's will, and they heavily relied on prayer as a source of healing and solace throughout their ordeal. Conversely, White participants framed their experiences with cancer in a secular context. They made no connection between God and their diseases, and did not mention resorting to prayer. Instead, they relied on secular mechanisms for coping with cancer, and attributed their healing to medical and technological advances. These findings enhance the understanding of how Black and White American cancer survivors differ in the use of religion as a coping mechanism for cancer.

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Discussion and Significance:

Participants' narratives offer several insights about their views on the cultural attitudes in question. In the case of fatalism, Black participants demonstrated a stronger belief in the predetermination dimension than their White counterparts, as they firmly believed that God predetermined their cancer. However, Black participants showed optimism rather than pessimism about their diagnoses, and they did not attribute cancer to bad luck. Black participants had a stronger belief in predetermination; but not a lower rate of cancer treatment than White participants. This means that stronger belief in cancer predetermination may not necessarily be a valid fatalism dimension.

One explanation for the lack of correlation between predetermination and pessimism is that, in the context of this research, predetermination did not carry the same negative connotation as pessimism and belief in bad luck, and participants in neither racial group considered the predetermination of cancers to be problematic. For Black participants, predetermination referred to God's will to give the cancer diagnosis. They countered this belief by believing in God's ability to treat them. For White participants, predetermination meant that cancer "just happens," which they countered with the confidence that medical and technological advances can treat it. In both cases, participants managed to get treatment for cancer rather than submitting to it. In other words, predetermination is not a valid dimension of fatalism if it is countered with a solution to the problem that is predetermined. It is possible that predetermination contributes to fatalism if it includes a sense of helplessness about the predetermined

problem. Future research on how individuals respond to helplessness may shed a light on when predetermination can be a dimension of fatalism.

Black participants' religious beliefs also influenced the levels of trust in their physicians. These participants looked at their physicians with high esteem and considered them as God's agents for healing. They believed that God endowed physicians with the knowledge and the skills to treat cancer. Such God-physician-connection belief added a dimension of physician trust for Black participants but not for White participants. This God-physician-connection became evident only when the three other dimensions were present (competency and honesty). Black participants who questioned their physicians' competence or honesty did not hesitate to seek second opinions; or to switch to other physicians. Overall, Black participants' view of physicians as God's agents for healing eliminated the physician trust gap between Black and White participants.

The God-physician-connection would have probably yielded a higher level of physician trust among Black participants than White participants had it not been for the three skeptics who spoke negatively of their experiences with cancer. The three skeptics lowered the overall average of Black participants' level in the qualitative analysis, as they constituted 20 percent of Black participants. However, a close examination of the skeptics' narratives reveals that their views are not the product of bad experiences with their physicians. They are the product of resentment towards the medical profession's history of racism, mistrust of the current health insurance industry, and the conflicting information they received from the internet.

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Mistrust in the health insurance industry stems from skeptics' suspicions about the industry's coverage practices. The for-profit nature of the health insurance industry creates an incentive for insurance companies to minimize payments on medical claims in order to maximize their profits. Insurance companies profit most from healthy individuals who pay their premiums but not use the medical services that these premiums are supposed to cover. Skeptics in the present research expressed suspicion that insurance companies prefer that insured individuals die at younger ages before getting stricken with age related diseases, including cancer.

Participants' narratives' pointed to the Internet as a potential source of undermining or boosting physician trust. One of the skeptics obtained different information about his diagnosis and treatment options from the internet than from his physician, which undermined his level of trust in his physician. Conversely, other participants attributed their high levels of trust towards their physicians to the fact that their physicians' management of their cancers matched management approaches they read online. While obtaining information from outside sources, has always carried some risk of receiving false information, obtaining medical information from the internet poses additional risks of misinformation. The internet has democratized the flow of information by putting much of this information at the fingertip of internet users. The problem with this democratization is that it allows for the flow of unverified and potentially misleading information (Cline & Haynes, 2001). Future research on how web-obtained medical information can affect patients' level of physician trust can help both physicians and web

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publishers streamline medical information that provide patients with more accurate information and maximize levels of physician trust.

Black participants' slightly higher level of social support is due to their association with fellow church members. While participants in both racial groups received social support from family and friends, Black participants had the added benefit of having a wider circle of support from their congregations. Congregation members helped relieve Black participants' anxiety about the cancer ordeal by listening to, and empathizing with Black participants. The success stories of these participants in defeating cancer encouraged congregation members to seek cancer screening and treatment, which, in turn, had a healing effect on Black participants. They developed more confidence in healing from cancer, and became more involved in making decisions regarding their treatment.

That Black participants were able to share their cancer experiences with, and receive social support from church members is a complete reversal of experiences of cancer patients in previous generations. Cancer patients in the past refrained from talking about their cancer diagnoses to avoid being stigmatized as not living according to God's will. The subsiding of the religious stigma around cancer allowed participants to receive social support of their religious groups. This finding is encouraging for individuals with other stigmatized diseases who can benefit from learning how removing stigma in a religious community can bring about a higher level of social support.

Finally, Black participants' religious beliefs increased their self-efficacy in comparison to White participants. Their belief in God as the one who heals their cancers

improved their confidence in beating cancer, which enhanced their ability to discuss treatment options with their physicians; and played a proactive role in their treatment. The religious belief in God in this case prevented the formation of a sense of helplessness that would have potentially increased Black participants' levels of fatalism.

The present research findings demonstrate that Black Americans' religious beliefs diminish the cultural attitudes that lead to cancer disparities between Black and White cancer survivors. These findings also demonstrate that not all Black Americans share the same cultural attitudes of fatalism, physician mistrust, social support and self-efficacy. Moreover, the present research finds that the above-mentioned cultural attitudes cannot be examined in isolation of religious beliefs, nor can they be examined in isolation of each other.

The present research findings indicate that a postpositivist worldview is appropriate for conducting this research. The postpositivist worldview rejects the reductionist positivist worldview that allows for a single observation and hypothesis only (Clark, 1993). In contrast, the postpostivitst worldview accounts for influences of natural surroundings; and offers multiple explanations (Creswell, 2014, 7). Findings of the present research debunk the positivist worldview that assumes all Black Americans to share the same cultural attitudes that hinder them from seeking cancer treatment. Instead, the present research accounts for the influence of religion in mitigating the cultural attitudes that hinder Black Americans from seeking cancer treatment. It also offers an alternative hypothesis about Black cancer survivors' cultural attitudes in relation to those of White participants.

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From a pragmatic perspective, findings of the present research can help the Black American community build on the successful experience of Black religious institutions in improving the lives of its members based on two points. First, the present research demonstrates that Black Americans' religious beliefs enhance their physician trust and self-efficacy, and provide them with an important source of social support. Second, as the literature indicates, Black religious institutions have successfully increased cancer screening rates among their congregation members.

The present research findings on physician trust and social support suggest two ways to increase cancer treatment rates. First, given the benefits that Black cancer survivors derive from congregation social support, Black churches can offer church-sponsored support groups where cancer survivors who were successfully treated tell their stories of beating the disease and encourage present and future cancer patients to seek treatment. Second, given the God-physician-connection among Black Americans that yields a high level of physician trust, Black churches can organize educational seminars on cancer. The churches can invite physicians, who are known and trusted among the Black community, to speak to congregation members about various cancers and the available treatment options, and debunk incorrect information that individuals may get from internet sources.

Patient Navigation Programs (PNPs) can benefit from findings of this research. PNPs have attributed the lack of increase in treatment rates among Black American cancer patients to navigators' failure to address the cultural barriers that those patients

face. Patient Navigation Programs can collaborate with Black churches to address the cultural barriers that their Black American patients face.

Finally, the present research findings fall in line with the Healthy People Program's objectives. The Program has been working under the auspice of Center for Disease Control and Prevention (CDC) and the Department of Health and Human Services (HHS) to reduce cancer disparities among Black Americans. It has set goals to reduce Black Americans' cancer death rate from 203.0 to 161.4 per thousand by 2020; and to increase the proportion of 5-year cancer survivor rate from 66.2 to 72.8 percent (Healthy People 2020, 2014). Program directors at the CDC and HHS can work with Black churches to achieve the Healthy People Program objectives.

IV. Study Limitations

The present research has three limitations: First, the self-selected, non-randomized nature, and small sample size limit the applicability of the research findings to the entire population of cancer survivors in the United States. Second, the Black participants in the present research are integrated with the White population. These participants live and work in predominantly White neighborhoods, which is not the case for all Black Americans. The present research may yield different results for segregated Black communities.

Third, both Black and White participants were free of cancer at the time of the interviews; and were in good health conditions. The present research may not apply to cancer survivors with more advanced stages of cancer. For example, cancer survivors

with late stages of cancer may have less self-efficacy as they lose their ability to be actively involved in their treatment. They may also become more fatalistic as they become helpless in the face of the spreading disease.

V. Suggestions for Expansion

The integration limitation in the present research provides direction for a future study on whether integration of Black Americans in White neighborhoods mitigates cancer disparities by eliminating cultural attitudes towards cancer treatment. Black participants in the present research may have the same cultural attitudes towards cancer because they live and work among a predominantly White population. In addition, it is not clear how Black participants in the present research developed their cultural attitudes. Comparative and longitudinal studies of between the cultural attitudes of Black American cancer survivors who are integrated in White neighborhoods and those who are segregated from them provides insights on how integration of Black and White Americans can reduce cancer mortality rates among Black Americans.

The effect of web-obtained information on physician trust also warrants more research. Getting stricken with a serious diagnosis, such as cancer, raises many questions in patients' minds about their diagnoses. These patients maybe more accepting to web-obtained information that may offer easier, cheaper, and more promising treatment results than information they receive from their physicians. The problem with such information is that it is often unscientific and potentially dangerous. The problem is compounded for individuals with preconceived suspicions about the

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medical profession and the health insurance industry, such as the skeptics in the present study. More research is needed on how Black Americans judge the veracity of web-obtained information in comparison to information they receive from their physicians.

VI. Conclusion

A comparative analysis of a sample group of Black cancer survivors and a matching White group of cancer survivors reveals that Black American cancer survivors who received adequate and timely cancer treatment have similar cultural attitudes towards cancer as White Americans. The two sample groups, however, differed in the extent to which they invoke God and religious beliefs in coping with cancer. Religious beliefs of Black American cancer survivors heavily influence their cultural attitudes towards cancer. These religious beliefs enhance their levels of physician trust, social support, and self-efficacy. Public and private programs can utilize findings of the present research to devise policies that can increase treatment rates among Black American cancer survivors.

Tables

Table 1: Schedule of Cases

Black/ White	Type	Stage	Age	Gender	Ins.	Marital status	Educ	Income $ (thousands)
1/1	Breast	2	70-79	F	Mcr/Prvt	S	High School	30-39
1/1	breast	2	50-59	F	Prvt	M	4 yr college	90-99
1/1	Prostate	early	60-69	M	Mcr/Mcd	M	4 yr college	40-49
1/1	Brain	1	30-39	F	Prvt	S	High School	10-19
1/1	Endometrial Ca in situ	2	30-39	F	Prvt	M	2 yr college	40-49
1/1	Colon	2	70-79	F	Mcr	S	4 yr college	10-19
1/1	Colon	1	50-59	F	Mcr/Prvt	M	High School	50-59
1/1	Prostate	1	60-69	M	Mcr/Prvt	M	High School	10-19
1/1	Prostate	1	50-59	M	Prvt/Mcr	M	4 yr college	50-59
1/1	Prostate	1	70-79	M	Mcr/Prvt	M	High School	10-19
1/1	Prostate	1	60-69	M	Mcr/Prvt	M	2 yr college	60-69
1/1	Prostate	1	70-79	M	Mcr/Prvt	S	4 yr college	60-69
1/1	Prostate	1	60-69	M	Mcr	S	High School	10-19
1/1	Prostate	1	70-79	M	Mcr/Prvt	S	High School	10-19
1/1	Bladder	2	60-69	M	Prvt	S	2 yr college	10-19

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Legend:
Ins. : Insurance type
Educ: Education level
Mcr: Medicare coverage
Prvt: Private coverage
Mcd: Medicaid coverage

Table 2: Fatalism Scale

	Black	White
1	60	36
2	48	30
3	37	43
4	35	31
5	24	15
6	45	43
7	30	19
8	42	29
9	50	26
10	37	41
11	58	35
12	24	44
13	36	37
14	32	44
15	24	32

F= 1.67
P= 0.174265

Mean (b) – Mean (w) = 5.1333
t= 1.36
p= 0.187057

No significant difference detected between the variances of the two samples

Table 3: Physician Trust

	Black	White
1	24	36
2	38	44
3	47	36
4	40	49
5	50	40
6	39	36
7	25	47
8	50	35
9	44	40
10	42	38
11	40	50
12	38	38
13	36	40
14	43	45
15	40	49

F = 1.97
P = 0.108484

Mean (b) – Mean (w) = -1.8
t = 0.76
p = 0.454871

Table 4: Social Support

	Black	White
1	35	56
2	35	44
3	42	46
4	54	49
5	55	50
6	35	37
7	44	43
8	53	43
9	28	44
10	42	44
11	40	41
12	48	41
13	46	44
14	43	47
15	42	38

F = 2.59
P = 0.042892

Mean (b) – Mean (w) = -1.66
t = 0.71
p = 0.483145

Table 5: Self-Efficacy

	Black	White
1	48	58
2	60	60
3	60	48
4	56	52
5	42	44
6	60	48
7	54	55
8	53	46
9	45	57
10	60	45
11	58	48
12	51	58
13	48	44
14	51	54
15	54	51

F = 1.11
P = 0.423971

Mean (b) – Mean (w) = 2.13
t = 1.03
p = 0.311526

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Table 6: Participants' references to religion

Black	White
I said lord I have too much to live for	It made me very uncomfortable when a couple of friends told me to come to church with them. I was very uncomfortable
I prayed, my friends prayed.	I am not a religious person.
I kind of [sic] knew that, maybe the holy spirit you might say	I feel it in me in heart in my own way, but I am not comfortable with going to church
I am Christian and I have a relationship with the lord	Thank God they were normal
thought oh my God what am I going to do	Depending on their religion, some people do better. Some people do not have religion to lean on.
trust God	The Lord will decide when we go and do not need to help him along
prayer is very important. Pray for healing	I am a good Christian man. If God wants to take me, open the book
I believe in God and I leave it God's hands	
My sister and brother felt like leave to God. God will give the doctor the knowledge of what to do	
leave it to God	
I am a man of faith. I am Christian.	
I said doc. Do you believe it God?	
Again I am a man of faith	
I go about and teach people about faith	
I just had faith in Lord if he wanted me to have cancer then he can heal it.	

Table 6: cont'd

Black	White
I just had faith in Lord if he wanted me to have cancer then he can heal it.	
my pastor and he prayed for me.	
I called my Bishop in St Thomas and he said he will gather the Elders and pray for me	
I survived it with God's will	
I believe that faith is very important to heal.	
I survived it, but with God's will	
Trust God a	
I am not a strong on faith	
I have a lot of family and I lot of praying family.	
I just went in with God on my side	
there was a lot of crying and praying	
if they are Christians or not Christians	
I would put God out there because if it wasn't for God I would not be here and if it was not for God, I would not be clear with it. It is all about God in my book	
Well lord whatever you can do	
I'll just let the man (pointing upwards) handle it	
I told them to pray for me.	
and the lord's hands.	
my family they prayed for me	
Being Christian they left in the hands of the lord and that is.	
They prayed for me	
I would say, lord, it is in your hands to let the doctor cure me	
God cured me from it	
Just pray.	
God gave him the knowledge and he went to med school	

Table 6: cont'd

Black	White
Let God guide my steps. I turn my life over to him prayer to the lord that I will be delivered	
I would say to them be prayerful	
I believe that I am delivered.	
I have faith in the lord	
I prayed about it	
and I prayed about it.	
I went to church and I had a testimony	
was leaving everything in God's hands	
I would say to pray, I know that God does things and he does it all through doctors I would tell them to pray	
praise God.	
I tell them to start praying. I tell them to pray. I tell them that God may have decided it is time for their loved one to go and that he was going to die so that if you do go, you go to the right place	

Table 7: Participants' references to the three dimensions of fatalism scale

	Black	**White**
Predetermination	There is nothing the I could do about it (bladder II) You have no control of it (colorectal II) God may have decided it time for them to go and that he was going to die (prostate I) If this is going to take me from this world, then I am willing to go (prostate I)	I figure that I cannot do anything about it If it was going to happen it was going to happen (prostate cancer I)
Luck	N/A	N/A
Pessimism	N/A	N/A

Table 8: Participants' references to the three dimensions of physician trust scale

	Black	**White**
Technical Competency	Dr. H. his reputation is crown so I kind a felt comfortable with him. ….He is the specialist, the expert. He knows what he is doing…Leave it in the hands of the professionals (bladder II) Go to M. because they are the best (brain I) I went to a medical surgeon, and he is the best (colorectal II)	So after reading about it I found that he was doing exactly what a doctor should do (brain I) The psychologist counseled me, telling me that I will be alright and they put me on anti anxiety medications and they were able to bring my back slowly (colorectal I)
Patient Needs	He has been examining my PSA and it was elevating. He said I need to keep up with you….The doctors were constantly watching me (prostate I) I was so sick. I could not walk by myself I needed help....He called the chemo and radiation and told them to stop. I told him that I prefer radiation...they supported my decision for radiation" 　　　　(Prostate I, Black)	The doctor said we will wait for 4 months. I went back in 4 months and it grew. So he said I want to do a biopsy so they did the biopsy and said you have the beginning of prostate cancer so he set me down explained to me that I had four ways to treat it (prostate I) Dr. H. did all the work. He set me up for having the radiation (prostate I) my doctor was on top of things. If it wasn't for her, the stubborn person I am, I would have not got treatment (prostate I)

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Table 8: cont'd

	Black	White
Honesty in Delivering Medical Advice	When I discussed the options with Dr. H. he recommended surgery and I asked him why he said because I am s surgeon and that is what I do. I told that I prefer radiation. He said I will send you to the best facility for radiation and he did. (prostate I) Dr. A. was saying let's get this test done, let's get this test done. I am glad I agreed with him and had the test done. (colorectal I) I asked him (the doctor) if he was sure and he said yes and said the test showed that 99% I had cancer (prostate I)	He said he could not deny me but he could not see a reason to remove a perfectly healthy breast, so I said ok. (breast II) I would expect an honest answer, and if he would, like Dr. H. (prostate I) When I did the research, I found out that the seeds kill not only the bad, they kill the good. The Dr. Said it I were to suggest anything the way the PSA is climbing, complete extraction (prostate I) I talked to the doctors about it, they thought it was a good idea that they would have done the same thing if they had the choice. (prostate I)

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Table 9: Participants' references to the three dimensions of the social support scale

	Black	White
Cognitive Support	One of the nurses at the hospital, like ambassador and she explained a lot of things to me (breast II) A lady in my church who had breast cancer a year before I did and I was asking her about Sloan-Kettering (breast II)	When the word came out …, I had telephone calls, people from church would come with shopping bags full of books about it..My daughter helped me with the dressings (breast II) I talked to the guys I was working with... Some guys said it is better to get it surgically removed, others said don't do that. I talked to at least 15 gentlemen (prostate I)

	Black	White
Material Support	My daughter has friends and her friends adopted me. They would call me up, and make sure I get what I need if I need to go to the grocery store they take me (colorectal II, 77 yrs old)	my girlfriend took me in while I was taking my chemo and radiation, I was staying with her….my brother came to get me (colorectal I, 50 yrs old)

Table 9: cont'd

	Black	**White**
Emotional Support	I had all my kids around me..... They were very supportive…My daughter was with me with all my chemo…I shared that with my pastor and the people at the church..I had the opportunity to share it with the congregation (breast II)

My husband said we will get through this together..,listen, you want to be mad, you want to cry and whatever (endometrial I)

He was constantly walking into the room would help me up and asked me if I needed anything (colorectal II)

She went with me to treatments and she was with me every step of the way. She wrote a poem and.. an affirmation and asked me to read it everyday. The affirmation states that I am alive and I will get better and that I am getting the best treatment out there (colorectal II)

My family they prayed for me and visited me at the hospital (prostate I)

My children and my wife were very supportive. They decided that if they were going to be strong they will be strong for their dad…they let me know that they were here for me….my pastor prayed for me. (prostate I) | So my son came when I went to have the surgery and stayed a couple of nights with me (breast II)

My brother would tell me to hang in there and that it will pass. he would throw comments like "when I had it...." and tell me what he went through. He really helped (brain I)

As for family and friends. They were for personal help...... they did what they could to help me stay strong. Everybody was sympathetic. People were more than willing to bend over (breast II) |

Table 10: Participants' references to the 3 dimensions of the self-efficacy scale

	Black	**White**
Have a Positive Attitude	Your mind has the capacity to heal. Just keep a positive outlook (breast II) I think a positive attitude is very beneficial to the health of the individual (prostate I) I did not let the diagnosis put in a position that I cannot function because I know that fear is the biggest enemy. It is like a bully so I did not let fear in….I survived with God's will (prostate I) I believe that I am delivered (prostate I) I don't let cancer get me (prostate I) Life is like night and day, when it is day, you know it will get night later, and when it is night, you know it will day later and I think this a good way to look at cancer, it is night that will be followed be day (colorectal II) I am a strong believer about a positive attitude (prostate I) do not give up (colorectal I) take it one day at a time (endometrial I)	Stay strong, stay positive. you gotta just be strong in your head (colorectal I) do not smother yourself in self pity (prostate I) I would not be as good as I do today if I did not get the treatment (prostate I) take it one day at a time, and Take life as it comes (prostate I) I have been very fortunate (colon II) Be grateful for what you have…The will to have the quality of life and do your best…..surround yourself with positive people. (breast II) Take better care of yourself (bladder II) I felt very very confident (prostate I)

Table 10: cont'd

	Black	White
Seek and communicate information	I engage with discussions where I can learn (prostate I) I went on line, did the research and saw what worked and made a decision based on my findings (prostate I) I had went to Moffit to see my options for treatment or just to have a hysterectomy I kept all my appointments, and when he saw something that he did not like he took to the specialist (bladder II)	I researched it I found out that it not only kills the bad, it kills the good (prostate I) I talked to a lot of people who had the test done and had it. My decision was let's get the prostate out (prostate I) …. asked the doctor what he would recommend (prostate I) I was not sure to have the hysterectomy but Dr. S. said I should (endometrial I)
Make health decisions	My next step was that I went to a medical surgeon, and he is the best (colorectal II) I did the research my self and made the decision which option I wanted (prostate I) I decided to go for the surgery because I had read in my research they worked for a while but after that there is high possibility of the cancer coming back (prostate I)	I am going to have the surgery), I will get it out 100% (prostate I) I decided to go for the mastectomy and started radiation (breast II) I chose the whole mastectomy rather than the lumpectomy. I asked to have the other breast removed (breast II) have a strong attitude that if you have cancer, let's get busy and get rid of it (colorectal I)

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Appendices

Appendix 1: mPFI: Powe Cancer fatalism scale.

Responses are measured on a 5-point Likert scale: 1=strongly disagree -5=strongly agree

I believe if someone is meant to have cancer, it does not matter what they eat. They will get cancer anyway

I believe if someone has cancer, it is already too late to do anything about it.

I believe someone can smoke all their life, and if they are not meant to get cancer, they will not get it.

I believe if someone is meant to get cancer, they will get it no matter what they do.

I believe if someone gets cancer, it was meant to be.

I believe if someone gets cancer, their time to die is near.

I believe if someone gets cancer, that is the way they were meant to die.

I believe getting checked for cancer makes people think about dying.

I believe if someone is meant to have cancer, they will have cancer

I believe some people don't want to know if they have cancer because they don't want to know they may be dying from it.

I believe if someone gets cancer, it does not matter when they find out about it, they will still die from it.

I believe if someone gets cancer a lot of different treatments won't make any difference.

I believe if someone was meant to have cancer, it does not matter what the doctor tells them to do, they will get cancer anyway.

I believe if someone is meant to have cancer, it doesn't matter if they eat healthy foods, they will still get cancer

I believe cancer kills most people who get it.

Appendix 2: Trust in physician sub-scale

Responses are measured on a 5-point Likert scale: 1=strongly disagree -5=strongly agree

1. I doubt that my doctor really cares about me as a person
2. My doctor is usually considerate of my needs and puts them first
3. I trust my doctor so much that I always try to follow his/her advice
4. If my doctor tells me something is so, then it must be true
5. I sometimes mistrust my doctor's opinion and I would like a second one (reverse score)
6. I trust my doctor's judgment about my medical care.
7. I feel my doctor does not do everything he/she should for my medical care
8. I trust my doctor to put my medical needs above all other considerations when treating my medical problems
9. My doctor is a real expert in taking care of medical problems like mine.
10.   I trust my doctor to tell me if a mistake was made about my treatment
11.   I sometimes worry that my doctor may not provide me with accurate information about my diagnosis

Appendix 3: Social Support Scale

Responses are measured on a 5-point Likert scale: 1=strongly disagree -5=strongly agree

 As much as I would like   Much less than I would like

1. Visits with friends and relatives
2. Empathy for my condition
3. Help with transportation from
   And to treatment sessions
4. Chances to talk openly to someone
   About my condition
5. Chance to talk openly to someone about how
   My condition is affecting my personal
   And family
5. Encouragement to start/continue treatment
6. Help around the house when I am sick in bed
7. Telephone calls to check on me
8. Useful advice about my condition and treatment
9. Invitation to go out when I physically can
10.   Chance to discuss treatment costs

Appendix 4: Self-Efficacy Scale

Responses are measured on a 5-point Likert scale: 1=strongly disagree -5=strongly agree

Understand and participate in care
1. I know that I will be able to deal with any unexpected health problems.
2. I am confident in my ability to understand cancer materials.
3. I am confident in my ability to understand my doctor's instructions.
4. It is easy for me to actively participation decisions about my treatment.

Maintain a positive attitude
5. I won't let cancer get me down.
6. It is easy for me to keep a positive attitude.
7. It is easy for me to maintain a sense of humor.
8. I am confident that I can control my negative feelings about cancer.

Seek and obtain information
9. If I don't understand something, it is easy for me to ask for help.
10. It is easy for me to ask nurses questions.
11. It is easy for me to ask my doctor questions.
12. It is easy for me to get information about cancer.

Appendix 5: Open-Ended Questions with Rationale for Each Question

1. How were diagnosed with cancer? Was your diagnosis the result of a routine screening, or something else?
This question checks for fatalistic attitudes. Research shows that fatalism contributes to lower rates of screening

2. What were your first thoughts when you were told that you had cancer?
This question also checks for fatalism. Cancer fatalism is the belief that a cancer diagnosis is a death sentence

3. After learning about your diagnosis, did you turn to anybody for advice? Who?
This question checks for provider (mis) trust. It assumes that patients who do not trust their providers will turn to alternative sources of healing, and vice versa.
The question also checks for social support by asking if the patient can get advice and help from others

4. Did you follow that advice?
This question is a follow up question to the previous one. It assumes that the patient will follow the advice of the trusted source, whether it is the doctor or a family member. The question check for provider (mis) trust

5. How did the people around you react to your diagnosis? Were they supportive?
This question checks for social support

6. Did your family, or anyone around suggest any alternatives?
This question checks for provider (mis) trust. It assumes that if the patient or their family do not trust the provider, they will the patient alternative health, or that they would tell the patient to dismiss the doctor'

7. Fast forward a few days after learning about the diagnosis, did you make any changes to your short term and long term future plans? Travel, work, etc…?
This question checks for fatalism, it assumes that patients who are expecting to die from their diagnoses will cancel long term plans and focus on the short term

8. Did your stand in the community change at all?
This question checks for social support

9. Did you discuss your thoughts about your diagnosis and treatment with anyone? Who?

10. How did you view cancer before and after your experience with the disease?

11. If a family member or a dear friend gets cancer, what advice would you give him/her, if they ask you for any?

12. What advice would you give to the patient's family members?

13. Could you describe for me the most important lesson that you learned from your experience with cancer?

13. Is there anything that you want to add?
The last five questions are catch-all questions to participants an opportunity to add anything they want to the information they provided

Appendix 6: Institutional Review Board (IRB) Approval Letter

December 10, 2013

Samar Hennawi
Government and International Affairs
Tampa, FL 33612

RE: **Expedited Approval for Initial Review**

IRB#: Pro00015100

Title: Reducing cancer disparities between African and White Americans by Increasing
         adherence to treatment among African American Cancer Patients

Study Approval Period: 12/10/2013 to 12/10/2014

Dear Mr. Hennawi:

On 12/10/2013, the Institutional Review Board (IRB) reviewed and **APPROVED** the above
application and all documents outlined below.

Approved Item(s):

Protocol Document(s):

Study protocol.doc

Consent/Assent Document(s)*:

informed consent.dox.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the
"Attachments" tab. Please note, these consent/assent document(s) are only valid during the
approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which
includes activities that (1) present no more than minimal risk to human subjects, and (2) involve
only procedures listed in one or more of the categories outlined below. The IRB may review
research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR
56.110. The research proposed in this study is categorized under the following expedited review
category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John Schinka, Ph.D., Chairperson
USF Institutional Review Board