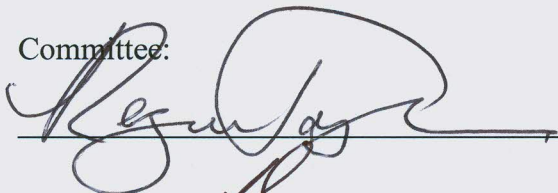


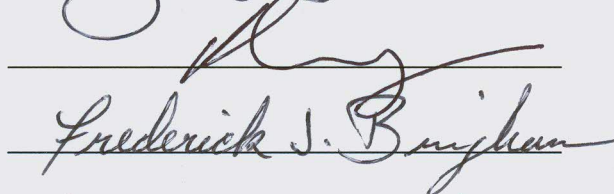
THE EXAMINATION OF MEDICAL MISTRUST AMONG NATIVE AND  
FOREIGN-BORN BLACKS LIVING WITH HIV/AIDS

by


Winifred F. Betts-Campbell  
A Dissertation  
Submitted to the  
Graduate Faculty  
of  
George Mason University  
in Partial Fulfillment of  
The Requirements for the Degree  
of  
Doctor of Philosophy  
Education

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Date: November 20, 2014 Fall Semester 2014  
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## **DEDICATION**

This doctoral dissertation is dedicated to my parents, Winifred and James, who taught me to dream big, reach for my goals, and supported me throughout this entire process. I am grateful for all that you have given me.

## **ACKNOWLEDGEMENTS**

I would like to thank the many friends, relatives, and supporters who have made this happen. I would like to thank my dissertation committee, Drs. Regine Talleyrand, Rita Chi-Ying Chung, Frederick Brigham, and Maria-Cecilia Zea for their unwavering guidance, assistance, and who have made the completion of this dissertation possible. Also, I would like to recognize Arthur, for your patience, kind words, and feedback. Your support means everything to me! Finally, I would like to acknowledge the two sites for allowing me to conduct my research with the population that they serve.

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## LIST OF ABBREVIATIONS AND SYMBOLS

Human Immunodeficiency Virus.....	HIV
Acquired Immunodeficiency Syndrome.....	AIDS
Tuskegee Study of Untreated Syphilis in the Negro Male .....	TSUS
The Centers for Disease Control and Prevention.....	CDC
Gay-Related Immunodeficiency Disease.....	GRID
National HIV/AIDS Strategy.....	NHAS
U.S. Office of Management and Budget.....	OMB
National Institute of Health.....	NIH
Medical Mistrust Index .....	MMI
Alpha coefficient.....	$\alpha$
Statistical Package for the Social Sciences.....	SPSS
Analysis of Variance .....	ANOVA
Not Applicable.....	N/A
Number of Participants within the Sample .....	N
Mean .....	M
Standard Deviation .....	SD
Standard Error .....	SE
Variance Inflation Factor .....	VIF
Unstandardized coefficients B .....	B
Standardized coefficients Beta .....	$\beta$
Number of degrees of freedom .....	$\kappa$
The World Health Organization .....	WHO
Internet Protocol .....	IP

## **ABSTRACT**

### **THE EXAMINATION OF MEDICAL MISTRUST AMONG NATIVE AND FOREIGN-BORN BLACKS LIVING WITH HIV/AIDS**

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George Mason University, 2014

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This dissertation examined medical mistrust among native and foreign-born Blacks living with HIV/AIDS who are currently receiving treatment in the United States. Medical mistrust plays a role in the extent to which Blacks access, receive, and continue with medical care. An examination of the literature on medical mistrust among Blacks living with HIV/AIDS was conducted and factors such as racial pride, religiosity, and communication were found to contribute to the development of medical mistrust within the Black community. A quantitative examination of medical mistrust due to differences in religiosity, racial pride, physician-patient communication, age, and sex among native and foreign-born Blacks living with HIV/AIDS was conducted. Three hypotheses were tested using one-way ANOVA and multiple regression analyses. Results from this study suggest that native-born participants may mistrust medical systems at a higher rate than their foreign-born counterparts. Further, pride in being Black and the communication

between patient and physician also seem to play a role in the level of trust that participants have towards their treating physician and the medical system. Finally, participants indicated that spirituality and talking to friends/family members served as coping mechanisms for them but participants were less willing to seek services from a counselor or psychologist to cope with their diagnosis. Implications for medical staff, counseling, prevention and future research are provided.

## **CHAPTER ONE**

The primary focus of this dissertation is to understand medical mistrust among native and foreign-born Blacks living with the human immunodeficiency virus (HIV) and the acquired immunodeficiency syndrome (AIDS) whom are currently receiving treatment and residing in the United States. Specifically, this study aims to determine whether a difference exists in the level of medical mistrust between native and foreign-born Blacks. Blacks compared to other racial/ethnic groups have higher levels of medical mistrust, which has been hypothesized to be linked to historical maltreatment of Blacks (Corbie-Smith, Frank, Nickens, & Elon, 1999; Freimuth, Quinn, Thomas, Cole, Zook, & Duncan, 2001; LaVeist, Nickerson, & Bowie, 2000). HIV seropositive foreign-born Blacks are triple stigmatized due to being born in a country outside of the United States, HIV seropositive, and Black. Foreign-born Blacks have been blamed by public health professionals and the federal government for introducing HIV to the United States (Amon & Todrys, 2008; Day, Park, Madras, Gumel, & Wu, 2006) and may express higher levels of medical mistrust than their native-born counterparts (Shippee et al., 2013).

According to the United States Census Bureau (2010) 13% of the United States population is foreign-born; this includes naturalized citizens, students, refugees, and undocumented immigrants. Since the 2009 travel ban restriction has been lifted (U. S. Department of Health and Human Services, 2009), there are now large groups of HIV

seropositive foreign-born individuals entering the United States (Prosser, Tang, & Hall, 2012). With only a few research articles addressing medical mistrust, HIV, and nativity differences (see Table 1), it is essential to understand the potential cultural differences that may influence medical mistrust within the Black HIV seropositive community, specifically nativity differences.

Cultural factors such as racial pride, religiosity, and communication will also be examined to determine whether there are nativity differences. No research to date has examined the potential link between medical mistrust and religiosity. To date, only one research has assessed the correlation between medical mistrust and racial pride (Shelton et al., 2010). In this study, Shelton and colleagues (2010) found that Blacks who had higher levels of racial pride also had higher levels of medical mistrust. However, this study did not examine racial pride among HIV seropositive Blacks. Further, potential languages barriers exist among foreign-born Blacks that may make it difficult to effectively communicate their wants and needs to their physician. Research has shown that physicians often have difficulty communicating about HIV (Wilson, 1997). In addition, Black patients receive lower quality of communication when at a physician's office compared to their White counterparts (Johnson et al., 2004). Significant cultural differences between native and foreign-born Blacks have been identified (Akinsete et al., 2007; Rosenthal et al., 2003). Specifically, foreign-born Blacks have less knowledge about HIV transmission and HIV related treatment services provided in the United States compared to their native-born counterparts (Rosenthal et al.), which suggests that communication about HIV is not occurring.

According to the Centers for Disease Control and Prevention (CDC) (2011a) Blacks in the United States are disproportionately affected by HIV/AIDS. One explanation for the racial difference in cases of HIV/AIDS is that Blacks are more likely to experience medical mistrust – that is, a lack of trust towards medical establishments and those that work in these establishments (Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004). According to the CDC (2013a), lack of access to medical services, which serves as preventative services, increases the susceptibility or vulnerability to contracting HIV/AIDS. Medical mistrust is prevalent within the Black community due to the historical mistreatment that Blacks have experienced dating back to slavery and the Tuskegee Study of Untreated Syphilis in the Negro Male (TSUS) (Corbie-Smith, Frank, Nickens, & Elon, 1999; Freimuth, Quinn, Thomas, Cole, Zook, & Duncan, 2001; LaVeist, Nickerson, & Bowie, 2000). Specifically, medical mistrust plays a role in the extent to which Blacks access, receive, and continue with medical care (LaVeist, Nickerson, & Bowie, 2000; Ravenell, Whitaker, & Johnson, 2008).

Numerous studies have shown that there are racial disparities in the delivery of medical services (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Halbert, Armstrong, Gandy, & Shaker, 2006; LaVeist et al., 2000). For instance, experimentations conducted during slavery and the TSUS are often times linked in the medical mistrust that Blacks experience (Freimuth et al., 2001; Gamble, 1997). Although there are inconsistencies in research regarding the origin of medical mistrust (White, 2005), it remains certain that mistrust exists within the Black community (LaVeist, Nickerson, & Bowie, 2000). Researchers believe that intergenerational transmission of medical

mistrust among Blacks has led to the development of HIV conspiracy beliefs in spite of HIV seropositive Blacks having never experienced slavery or the TSUS firsthand (Freimuth et al., 2001; Thornburn-Bird & Bogart, 2005). Because of the exposure to experimentation and medical abuse experienced by Blacks in the past, it is not surprising that research has found higher levels of medical mistrust within the Black community (Randall, 1996).

The review of the literature on medical mistrust has transitioned from examining racial and ethnic differences in the general population (LaVeist et al., 2000), cancer patients (Halbert et al., 2009), and individuals who smoke (Nawaz et al., 2012), to the effects of personal characteristics and experiences (Benkert, Peters, Clark, & Keves-Foster, 2006; Hammond, 2010) and historical events (Brandon, Isaac, & LaVeist, 2005; Gamble, 1997). Regardless of the setting and type of medical services being rendered, in general, Blacks tend to mistrust health care establishments, physicians, and the medical system at a higher degree than their non-Hispanic White counterparts (Armstrong, Hughes-Halbert, & Asch, 2006). Lastly, Thrasher, Earp, Golin, and Zimmer (2008) indicate that among ethnic and racial minorities, higher levels of discrimination were associated with lack of trust, lower levels of beliefs that HIV related care would be beneficial, and lower levels of medication adherence. Regardless of racial identity, numerically there are more native-born individuals living with HIV compared to their foreign-born counterparts (Prosser, Tang, & Hall, 2012), however, the number of HIV seropositive foreign-born individuals living in the United States is increasing (Johnson, Hu, & Dean, 2010). Research has shown that the percentage of HIV seropositive foreign-



born Blacks, specifically those born in Africa, is more likely to be higher than their native-born counterparts (Johnson, Hu, & Dean; Kerani et al., 2008). Although research shows that Blacks may experience medical mistrust, very few studies have examined the levels of medical mistrust based on nativity.

Chapter One will provide an overview of the importance of examining medical mistrust including specific explanations of medical mistrust among Blacks. In chapter two, the distinction between trust, distrust, and mistrust within the health care system and sociopolitical and historical information regarding medical abuse, will be discussed in detail. Also, an examination of the medical mistrust literature will be provided. Finally, the constructs of interest in this study will be introduced. The research methods, research questions, and hypothesis are explained in chapter three.

## **Background**

HIV is a virus that attacks the immune system and makes it difficult to combat infections (Delaney & O'Brien, 2012). Regardless of race/ethnicity, gender, religion, socioeconomic status, and sexual orientation, HIV/AIDS affects millions of individuals globally. In 2009, there were roughly 33.3 million people living with HIV worldwide (Joint United Nations Programme on HIV/AIDS, 2010). Of the 33.3 million people living with HIV, 1.2 million were in the United States (CDC, 2012a), this is less than 1% of the total United States population, and 20% of the 1.2 million were unaware of their HIV serostatus (CDC, 2012b). Consequently, research has shown that 54% of new infections within the United States are a result of those who are unaware of their HIV serostatus (Marks, Crepaz, & Janssen, 2006). More than half (22.5 million) of the 33.3 million

individuals living with HIV/AIDS worldwide are in Sub-Saharan Africa; 460,000 reside in Middle East and North Africa; and 240,000 are in the Caribbean (Joint United Nations Programme on HIV/AIDS, 2010). Although HIV/AIDS does not discriminate, in the United States, Blacks are disproportionately represented in the HIV seropositive population (CDC, 2011a) making up 44% of all new HIV seropositive cases in the United States (CDC, 2013a).

The origin of HIV has been linked to transmission of the simian immunodeficiency syndrome virus from monkeys to humans (Worobey et al., 2008). The transmission most likely occurred when hunters in Africa were exposed to the infected blood of chimpanzees (Worobey et al.). Despite this scientific explanation surrounding the origin of HIV, 48% of Blacks believe that HIV was manmade by the government in order to eradicate the Black population in the United States (Bogart & Thorburn, 2005). While, the fear that Blacks in the United States hold of being eradicated can be traced back to slavery (Harris, Gorelick, Samuels, & Bempong, 1996), research has conveyed that conspiracy beliefs associated with HIV also exist internationally, in countries such as South Africa (Tun et al., 2011). Specifically, many Black South Africans believed that the HIV was created by the United States government as a way to eradicate Black South Africans during apartheid (Niehaus & Jonsson, 2005).

The HIV allegedly arrived in the United States in the mid to late 1960's (Stine, 2010). In the United States, the first cases of HIV were reported by the CDC among five young homosexual males who presented with similar symptoms, Kaposi's sarcoma (CDC, 1981a). Kaposi's sarcoma, according to the American Cancer Society (2013), is a

cancer that appears as a purple, red, or brown tumor on the skin and mouth. While racial identification was not reported in these initial cases (CDC, 1981b), subsequent images of those dying from HIV/AIDS portrayed White homosexual men (Simone, 2012).

However, according to Gavett (2012) the sixth and seventh man diagnosed with HIV were Black, indicating that Blacks were as affected with this virus as their White counterparts from the beginning of this epidemic in the early 1980s. It was not until July 3, 1981 that the CDC provided information regarding the race of the HIV seropositive individuals (CDC, 1981b). During the early years, HIV/AIDS was predominately linked to homosexual males, resulting in it being referred to by its former name, gay-related immunodeficiency disease (GRID) (Alcamo, 2002). Although a majority of those initially diagnosed with HIV/AIDS were White (Simone, 2012), today, the majority of HIV cases can be found among ethnic and racial minorities, specifically Blacks (CDC, 2011a).

According to the CDC (2011a) Blacks have the highest rate of HIV compared to any other racial and ethnic group in the United States. While Blacks make up roughly 13.1% of the United States population (United States Census Bureau, 2013a), Blacks account for almost half (44%) of all new HIV infections (CDC, 2013a). Not only are Blacks disproportionately represented in new infections, but they also have the highest rate of AIDS-related deaths (Moore, Onsomu, Timmons, Abuya, & Moore, 2012; Oramasionwu et al., 2009). In 2010, Black men accounted for 70% and Black women accounted for 29% of all new HIV infections among Black adolescents and adults (CDC, 2013b). From the available data of the HIV seropositive Blacks residing in 33 states, which was collected between the years of 2001 to 2007, and obtained place of birth,

roughly 11.7% or 11,702 were foreign-born (Johnson, Hu, & Dean, 2010). More than half (54.1%) were born in the Caribbean and 41.5% were born in Africa (Johnson, Hu, & Dean).

The CDC (2013a) revealed that one in 16 Black men and one in 32 Black women will be diagnosed with HIV within their lifespan. Furthermore, AIDS is in the top five leading causes of death among Blacks in the United States between the ages of 25 and 44 (CDC, 2013a). The percentage of foreign-born Blacks within the HIV seropositive Black community in the entire United States has not been measured (Kerani et al., 2008) therefore it is difficult to determine the prevalence of HIV within the foreign-born Black community. However, when a disease disproportionately affects one racial group, it is imperative to understand factors that may contribute to the high rate of infection among that group.

One speculation as to why Blacks are hardest hit by the HIV/AIDS is due to medical mistrust and the stigma associated with having a HIV/AIDS diagnosis (Bogart, Walt, Delahanty, & Figler, 2004; Gamble, 1997). There are many factors that can contribute to the development of mistrust, specifically cultural mistrust, such as racism, discrimination, historical events, personal experiences, as well as many other factors (Shoff & Yang, 2012). Cultural mistrust is "...the belief acquired by [Blacks], due to past and ongoing mistreatment related to being a member of that ethnic group, that Whites cannot be trusted" (Terrell, Taylor, Menzise, & Barrett, 2009, p. 299), specifically, the mistrust of society (Mosley, Freed, Bullard, & Goold, 2007). Cultural mistrust is prevalent within four domains: education and training, business and work, interpersonal

and social relations, and politics and law (Terrell & Terrell, 1981). Mistrust towards all systems continues to prevent many Blacks from trusting services provided within these systems. However, for the purpose of this dissertation, the primary focus will be on medical mistrust.

Medical mistrust is a lack of trust towards medical establishments (e.g. hospitals, clinics, and physician office) and those that work in these establishments (e.g. nurses and physicians) (Thompson et al., 2004). Trust is fundamental to the relationship between medical establishments, public health officials, physicians and their patients. Trust affects a patients' willingness to seek services (Bogart et al., 2004), provide health information (Hall, Dugan, Zheng, & Mishra, 2001), to consent to receive treatment and to adhere to the treatment recommendations (Hall et al., 2001), to be pleased with services (Bogart et al., 2004), and to continue services with the same physician (Thom, Hall, & Pawlson, 2004). Trust is inescapable in the medical field; the more a patient is in need of the physicians' services, the greater the awareness of susceptibility, and the higher the potential for trust (Hall et al., 2001).

Mistrust of physician and medical facilities is problematic because it negatively affects an individual's health (Thom & Campbell, 1997), weakens prevention and treatment efforts (Hall et al., 2001), and leads to health inequalities between racial and ethnic groups (Pearson & Raeke, 2000), specifically within the Black community (Freimuth et al., 2001; Gamble, 1997; LaVeist et al., 2000). Blacks, compared to other racial and ethnic groups, are more likely to consider that physicians will conduct harmful experimentation during their routine medical care (Jacobs, Rolle, Ferrans, Whitaker, &

Warnecke, 2006) without written or verbal consent (Boulware et al., 2003), provide inadequate and inferior quality of care than that of what is provided to Whites (Jacobs et al., 2006), and treat Blacks unjustly because of the color of their skin (Thompson et al., 2004). Since medical mistrust hinders access to health related services and therefore optimal health, it should be addressed among Blacks in order to decrease the rate of HIV/AIDS infections and to increase treatment among Blacks.

Understanding the various aspects that impact the acquisition and transmission of HIV/AIDS in the Black community is imperative. The CDC (2007) have established a “Heightened National Response to Address the HIV/AIDS Crisis” in the Black community which is committed to increasing and developing effective prevention and intervention, boost diagnosis and care, and establish public collaboration and contribution. It is essential to understand mistrust of medical institutions, providers, and services within the Black community, specifically those living with HIV/AIDS, so that effective interventions and preventative methods can be established. The White House has recognized the disproportionate representation of HIV/AIDS among Blacks and has established the National HIV/AIDS Strategy (NHAS) in order to address HIV/AIDS in the Black community. Specifically, Blacks are among the four target high-risk populations identified by the NHAS. The NHAS’s vision states that:

The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity, or socio-economic circumstance, will have unfettered

access to high quality, life-extending care, free from stigma and discrimination.

(White House Office of the National AIDS Policy, 2010, p.3).

Moreover, the NHAS for the United States indicates that by target year 2015, there will be a 20% increase in the percentage of HIV seropositive Blacks with untraceable viral loads (White House Office of National AIDS Policy, 2010). Having an untraceable viral load suggests that the individual has relatively low levels of HIV in his or her system which in turn reduces the risk of HIV transmission via sexual intercourse (Wilson, Law, Grulich, Cooper, & Kaldor, 2008). One aspect that researchers have identified as affecting the Black community is that, although Blacks may be linked to health care services, their access to health care often remains irregular and fragmented, rather than continuous, comprehensive, integrated, and coordinated (LaVeist, Nickerson, & Bowie, 2000; Ravenell, Whitaker, Johnson, 2008). Since medical mistrust has been identified as an aspect that prevents Blacks from seeking and retaining medical services (LaVeist et al., 2000; LaVeist, Isaac, & Williams, 2009), understanding the impact of medical mistrust among native and foreign-born Blacks living in the United States could potentially assist practitioners in addressing these health disparities. It is difficult to determine whether foreign or native-born Blacks living with HIV/AIDS hold higher levels of mistrust since very few researchers have examined and differentiated the two groups. A study conducted by Shippee and colleagues (2013) determined that foreign-born individuals had higher levels of distrust towards traditional medicine compared to their native-born counterparts. However, participants' HIV serostatus were not identified and the individuals were from various racial and ethnic groups. Without differentiating

between the two groups, the results may be misleading (Johnson, Hu, & Dean, 2010) suggesting that all Blacks have medical mistrust and could contribute to the lack of effective intervention and preventions that have been established.

### **Statement of Purpose**

Race and ethnicity are often variables examined when seeking to understand HIV/AIDS, particularly since research suggests that HIV/AIDS drastically impacts ethnic/racial minorities (Hemmige, McFadden, Cook, Tang, & Schneider, 2012). Frequently the term “race” is used as a demographic variable in empirical studies, however, researchers rarely assess within group cultural differences among Blacks. More specifically, the words “African American” and “Black” are used interchangeably and the ethnic, cultural, or within group differences of those who are classified and self-identify as “African American” and “Black” are often overlooked. Nativity is often not addressed when using the term “African American” or “Black”. Failure to define and distinguish the potential differences in nativity within the Black community may provide misleading results in research. For example, using the term “African American” and “Black” interchangeably may imply that all individuals within the study are “American” or native-born, when in fact those born outside of the United States may have been included in the research study. Understanding the potential cultural differences is beneficial when attempting to provide culturally appropriate health intervention and prevention services (Johnson, Hu, & Dean, 2010). Further understanding of these differences can assist in developing effective services that are aimed at decreasing the transmission and acquisition of HIV/AIDS among the Black community (Johnson, Hu, & Dean).



Although the use of the term race to categorize individuals can be traced back to the 1900s (Lee, 1993), in 1978, the United States Office of Management and Budget (OMB) required that all federal agencies use a minimum of four race categories: “American Indian or Alaska Native”, “Asian or Pacific Islander”, “Black”, and “White” (OMB, 1978, 1997). The definition of “Black” is “a person having origins in any of the Black racial groups of Africa” (OMB, 1997). The current standards utilize five categories, with the previous term “Black” being modified to “Black or African American” and the definition revised to “a person having origins in any of the Black racial groups of Africa. Terms such as ‘Haitian’ or ‘Negro’ can be used in addition to ‘Black or African American’” (OMB, 1997).

Kressin, Chang, Hendricks, and Kazis (2003) indicate that racial/ethnic statistics will contrast depending on the statistical gathering methods. Using meaningful racial/ethnic categorization is vital and of increasing concern due to the various health disparities (Smedley, Stith, & Nelson, 2003) and the growing number of Blacks living with HIV/AIDS (CDC, 2007). The number of persons living with HIV/AIDS in the United States who are foreign-born (both legal and illegal) is increasing (Kent, 2005), yet very few articles examine HIV within the foreign-born population (Johnson, Hu, & Dean, 2010). Only a handful examine the differences between Blacks who are foreign and native-born, which could be an important distinction to make given the large numbers of Blacks living with HIV/AIDS (Johnson, Hu, & Dean).

Despite the extensive research, programs, and advocacy that have occurred within the United States, many have ignored the difference between native and foreign-born

Blacks. Thorough comprehension of the differences in medical mistrust between native and foreign-born Blacks is critical to guarantee that culturally specific treatment, intervention, and prevention approaches are created appropriately. These treatment, intervention, and prevention services may differ based on nativity. Tailoring effective treatment services to address the culturally specific factors of native and foreign-born Blacks could have substantial implications for HIV prevention such as potentially decreasing the transmission and acquisition of HIV within the Black community (Johnson, Hu, & Dean, 2010).

To address this critical gap in current research, this study aims to identify difference in medical mistrust between foreign-born and native-born Blacks living with HIV/AIDS. The purpose of this study is to determine if differences exist in medical mistrust among native and foreign-born Blacks living with HIV who are currently receiving treatment. Specifically to understand the potential cultural factors (racial pride, religiosity, and communication) that may contribute to medical mistrust.

### **Definitions**

For the purpose of this study, the following terms will be defined: medical mistrust, Black and African American, foreign-born, native-born, HIV, AIDS, spirituality/religion, racial pride, and communication.

**Medical mistrust.** Medical mistrust is defined as a “lack of confidence in medical techniques, as well as beliefs that members of certain ethnic groups do not receive accurate medical information, are treated insensitively, and receive inferior care compared to other groups” (Thompson et al., 2004, p. 211). Medical mistrust involves

and evokes negative emotions, specifically fear and suspicion, due to the historical unethical treatments that one's race has experienced (Thompson et al., 2004).

**Black.** The term "Black" will be used as an all-inclusive term that refers to individuals of African diaspora, regardless of cultural identification. Within this dissertation, the term "Black" will replace all terms such as African American, Black American, African and individuals who identify as Kenyan, Nigerian, or Haitian to name a few (United States Census Bureau, 2013b).

**Foreign-born.** The term foreign-born will refer to those who were born in another country other than the United States and who were not United States citizens at birth.

**Native-born.** The term native-born will refer to all of those who were born in the United States and/or were United States citizen at birth. This includes those who were born overseas due to military deployment but are considered United States citizens.

**Human immunodeficiency virus.** The HIV is a permanent virus that can lead to AIDS. There are two types of HIV: type 1 and type 2. Type 1 is prevalent worldwide, whereas type 2 is mostly found in West Africa (CDC, 2011b). Although both HIV type 1 and 2 have the same route of transmission and both can cause AIDS, type 1 and type 2 differ in the disease progression (CDC, 2011b). Since the purpose of this paper is to address HIV in the United States, the term HIV will primarily refer to HIV type 1. In addition, when the term "HIV" is used it will only reference those who have been diagnosed and have been told that they have HIV. The term HIV will exclude the diagnosis of AIDS.

**Acquired immunodeficiency syndrome.** The term AIDS refers to those who have been diagnosed with stage 3 of the HIV infection. The identification of AIDS includes the diagnosis of certain opportunistic infections; such as Kaposi's sarcoma, recurrent pneumonia, toxoplasmosis of the brain, and lymphoma of the brain; and/or a decrease in CD4 cells (CDC, 2012c).

**Spirituality/religion.** The term religiosity is a concept related to religion. Religiosity involves the emotional, behavioral, intellectual, relational, and physical processes connecting religion and spirituality (Miller & Thoresen, 2003). The term spirituality is more individualistic and a subjective element of religious experiences and the literature implies that both spirituality and religion are entwined (Miller & Thoresen, 2003). The interconnection between spirituality and religion is often referred to as spirituality/religion (Szaflarski et al., 2006).

**Racial pride.** Racial pride is the importance that an individual attaches to his or her racial group and it has been shown to increase receptiveness and acceptance of health services (Landrine & Klonoff, 1995).

**Communication.** The term communication is a concept related to the quality of the physician and patient's overall health communication from the perspective of the patient. Communication includes the physician's explanation of test results, potential health risks, and symptoms. In addition, communication is the patient's perspective as to whether the physician exhibited sympathy and compassion for the patient and his or her health concerns (Wilson & Kaplan, 2000).

## **CHAPTER TWO**

Various specializations have examined HIV/AIDS within the Black community. One aspect that continues to provide vital and insightful information to each profession is medical mistrust. The lack of trust that one holds towards his or her physician hinders the individual's ability to access, receive, and remain in health related services. Although medical mistrust has been identified as one factor that contributes to the high rate of HIV/AIDS within the Black community, no research to date has examined the potential cultural and racial differences in medical mistrust between native and foreign-born Blacks. A majority of the medical mistrust literature aggregates native and foreign-born Blacks and does not delineate the nativity of the participants. Aggregating the studies sample provides generalizable results that are not culturally tailored to the diversity of the population, which in turn may make treatment, prevention, and intervention efforts inadequate. Medical mistrust should be addressed among native and foreign-born Blacks in order to decrease the rate of HIV/AIDS infections and to increase effective treatment services. Further, understanding potential cultural and racial differences can aid in establishing effective interventions and prevention methods. This dissertation aims to provide crucial information regarding the potential cultural differences between native and foreign-born Blacks living with HIV/AIDS so that this information can be used to provide effective and culturally sensitive treatment, prevention, and intervention services.

In this chapter, the cultural-ecological theory, definitions and a distinction between trust, distrust, and mistrust will be examined. Further a synopsis of sociopolitical and historical factors of medical mistreatment within the Black community will be provided. This segues to medical mistrust among foreign-born Blacks living with HIV/AIDS. Lastly, presented is an overview of the medical mistrust literature and racial and cultural factors that influence mistrust amongst those living with HIV/AIDS.

### **Cultural-Ecological Theory**

In order to understand the cultural differences that both native and foreign-born Blacks have, a conceptualization of John Ogbu's cultural-ecological theory (Ogbu & Simons, 1998) must be examined. The cultural-ecological theory identifies two types of minorities (a) voluntary (immigrant) minorities, and (b) involuntary (nonimmigrant) minorities and explains their response to racism, specifically at the hands of "White America" (p. 158). Ogbu indicates that to be considered a minority one must be dominated by another group, specifically the positions of power that one holds within the same country or society is less than that of the majority.

Immigrant minorities, according to Ogbu and Simons (1998), historically, have voluntarily become a part of society and do not typically experience hardships. Immigrant minorities, also known as voluntary minorities, willingly moved from their country of origin to the United States in order to obtain better opportunities (education, employment, financial, etc.) and freedom (religious, political, etc.). The individuals within this group are typically different than those in the majority group based on their race/ethnicity, religion, and/or language. Voluntary minorities typically experience

discrimination due to cultural and/or language differences. Children of immigrant minorities are considered to be voluntary minorities regardless if they decided to immigrate to the United States or are in the United States due to birth. This applies to second-, third-, and fourth-generation United States born minorities. An exception to this rule are descendants of immigrants who share kinship with involuntary minorities, that is, those who were brought into the United States against their will.

The involuntary minorities are those who were brought to the United States involuntarily during slavery and other colonization periods or view that their existence within the United States was forced upon them and their people. The individuals within this group are typically different than those in the majority group based on their race/ethnicity, religion, and/or language. Due to the cultural and language difference, involuntary minorities experience hardships and are not typically successful within the various systems (educational, political, etc.). Involuntary immigrants respond to their history (slavery) in the United States and these historical influences impact their perceptions and responses to the various systems (education, medical, social, etc.).

Ogbu and Simons (1998) explains four ways in which minorities make sense of, behave in, and guide their world, which he calls the cultural model differences. The four ways of understanding are (a) status frame of reference, (b) instrumental responses, (c) trust in White institutions, and (d) symbolic response and collective identity. For the purpose of this dissertation, the trust in White institutions is most applicable and will be discussed. In the trust in White institution, voluntary minorities, upon arrival, interpret the various institutions and systems (educational, medical, social, etc.) within the United

Sates optimistically. Voluntary minorities do not scrutinize the authorities within these systems and conform to the rules of each system. By conforming voluntary immigrants believe that they have a higher chance of being successful. Voluntary immigrants have “pragmatic trust” which is trust that one holds towards institutions lead by Whites due to the optimistic view and attitude that one has upon arriving into a new country (Ogbu & Simons, 1998).

On the contrary, involuntary minorities do not view the institutions and systems optimistically. Involuntary minorities do not trust these systems due to discrimination, racism, and historical events that have led to distrusting the institutions and systems that are controlled and lead by Whites. In addition, involuntary minorities do not believe that these systems will provide adequate and appropriate services to their children as compared to their White counterparts. A detailed examination of trust, mistrust, and sociopolitical and historical examples that impact minorities, specifically Blacks, trust are provided below.

### **Patient Trust**

Trust is a crucial element in the health care system; it is fundamental to the relationship that the patient and physician will develop (Hall et al., 2001). Trust provides importance and significance to the relationship and is valued by both the patient and physician (Hall et al., 2001). Patients who hold a high level of trust in their physician also have been shown to have a high level of medication adherence and continuity of health care services (Mainous, Kern, Hainer, Kneuper-Hall, Stephens, & Geesey, 2004; Thom, Ribiskl, Stewart, & Luke, 1999). A study conducted by Thom et al. (1999) expressed that



trust affects the psychological well-being, level of anxiety, and healing within a patient. Further, trust plays a role in the level of helplessness experienced by a patient. Goold (2001) expressed that helplessness and vulnerability are developed when a patient becomes ill, lacks power within the relationship between the patient and physician, and lacks the knowledge about his or her illness and health. Further, patients give control to the physician in order to gain perspective that the patient believes that he or she needs, such as positive health outcomes (Goold, 2001). In order to fully understand the concept of trust, a detailed description of the words trust, distrust, and mistrust will be reviewed.

Trust can be differentiated into two categories, institutional and interpersonal trust (Calnan & Rowe, 2006; Pearson & Raeke 2000). Interpersonal trust is the patient's dependence on his or her physician's ability and character (Calnan & Rowe, 2006; Pearson & Raeke 2000); whereas institutional trust focuses on the patients' reliance towards the health care organization or health care system (Calnan & Rowe, 2006; Pearson & Raeke 2000). Trust within a healthcare system is a sociological concept that refers to a patient's outlook towards the future (Cook, 2001). This outlook is typically positive in nature, with the expectation of a good outcome, and goodwill expressed by the physician or health care institution (Cook, 2001). Words such as "confidence" and "faith" can be used to describe the term trust and are often times used interchangeably (Hupcey, Penrod, Morse, & Mitcham, 2001). Trust involves the acceptance that in a helpless situation, the patient believes that the physician/healthcare organization will act in the best interest of the patient (Hall et al., 2001; Thom et al., 2004). Previous experiences with hospitals, physicians, and health care systems influence the degree of trust awarded

to a physician (Cook, 2001). Goold, Fessler, and Moyer (2006) indicate that trust in physicians is affected by an individual's overall level of general trust, prior experiences, messages, and knowledge provided by others. A patient's health also affects the level of trust towards a physician. For instance, patients with significant health concerns tend to have lower levels of trust compared to those who had better health (Balkrishnan, Dugan, Camacho, & Hall, 2003).

Distrust involves the lack of a positive attitude towards the physician or healthcare establishment (Hall et al., 2001). Distrust involves the lack of or nonexistence of trust, holding pessimistic views towards the results or motivation of the physician, and wariness in which the patient can trust the health care provider but will need to verify accuracy of the results or statements (Govier, 1992). Patients who have distrust view health outcomes negatively (Hall et al., 2001). Distrust is on one end of the continuum with trust and therefore it is virtually impossible to be both trusting and distrustful (Hall et al., 2001).

### **Concept of Medical Mistrust**

It is important to note that experiencing racism and discrimination increases levels of mistrust across all systems (e.g. educational, criminal justice, social etc.) and not solely medical mistrust. However, for the purpose of this dissertation, mistrust within the medical system will be the sole focus. Medical mistrust is defined as a "lack of confidence in medical techniques, as well as beliefs that members of certain ethnic groups do not receive accurate medical information, are treated insensitively, and receive inferior care compared to other groups" (Thompson et al., 2004, p. 211). This suggests

that physicians and medical establishments have the potential to engage in malicious and unethical practices (Thompson et al., 2004). This working definition of medical mistrust includes negative feelings, attitudes, and fear of being mistreated due to one's race/ethnicity, experiencing discrimination, and includes suspicion due to the historical and sociopolitical context. Medical mistrust can be differentiated from the concept of distrust in that it involves and evokes negative emotions, specifically fear and suspicion, due to the historical unethical treatments that one's race has experienced (Thompson et al., 2004).

A vast amount of the literature surrounding trust and mistrust of medical services is in the medical, public health, and epidemiological fields based on the result yielded from the literature review. Most of the literature focused on White men. Thus the development of the National Institute of Health (NIH) Revitalization Act was put into place to have a representative sample of two groups that were not being captured in research, minorities and women (NIH, 1993). The purpose of the Revitalization Act was to recruit those from disadvantaged backgrounds to participate in biomedical and behavioral research, specifically making it a requirement that women and minorities are included in this research. Subsequent research following the Revitalization Act was conducted to understand racial and ethnic differences as it relates to participation in biomedical research, specifically to explore the potential differences that women and minorities may have (NIH, 1993). During this time, early research identified discrimination, distress, and mistrust as aspects that were preventing Blacks from participating in biomedical research. Further mistrust in other health care services such as

the patient-physician interaction (Wilson & Kaplan, 2000), hospital (LaVeist et al., 2000), and the government (Bogart & Thorburn, 2005; Klonoff & Landrine, 1999) were identified. The next section will describe in detail, historical and sociopolitical factors that shape Blacks' mistrust towards the health care system.

### **Sociopolitical Context**

There are innumerable significant racial discriminations, medical mistreatment, and sociopolitical contexts that shape Blacks' mistrust towards physicians and health care systems. Blacks' negative perception of physicians and the health care systems is the results of countless years of experiencing discrimination, racism, and medical abuse (Byrd & Clayton, 2000; Gamble, 1997). Historically, the high rates of death and disease among Blacks were seen as a result of innate racial defects that made Blacks physically and biologically different than Whites (Patterson, 2009). Experience of medical mistreatment and discrimination is evident by the TSUS (Byrd & Clayton, 2002; Gamble, 1997), and the story of Henrietta Lacks (Skloot, 2010) both which will be discussed later in this paper. Medical institutions previously suggested that Blacks were sexually promiscuous, deceitful, could only be submissive, and were intellectually ill-equipped to make medical decisions (Genovese, 1976). These statements were used to rationalize atrocious testing and treatment of Blacks, which infused and perpetuated their fear and mistrust of medical establishments (Suite, La Bril, Primm, & Harrison-Ross, 2007). An overview of the sociopolitical and historical events that influence the development of medical mistrust in the Black community is provided.

**Slavery.** Throughout the history of medicine, human subjects have been a necessary and useful teaching tool (Savitt, 1982). However, during the 246 years in which slavery existed in the United States, Blacks, specifically those living in the antebellum South, were treated as guinea pigs in medical schools (Dula, 1994; Harris, Gorelick, Samuels, & Bempong, 1996). Access to Black slaves was particularly easy due to the lack of advocacy and voice that Blacks held during this time (Savitt, 1982). Blacks were dissected and experimental autopsies were conducted (Harris et al., 1996).

Due to mistreatment, Harris et al. (1996) conveyed that many Blacks expressed wanting to die during the summer months so that their bodies would not become subject to these experiments. Ironically, death did not prevent medical professionals from experimenting on the corpses of Blacks (Fett, 2002). Even in the postbellum South, Blacks continued to be used as guinea pigs by doctors who would steal bodies of Blacks during the night (Harrell, Callaway, & Power, 1993; Savitt, 1982). The bodies that were stolen were of living Blacks, who were subsequently killed and dismembered (Fry, 1975; Savitt, 1982). In addition, graveyards were regularly robbed so that corpses of Blacks could be dissected and inspected (Fett, 2002; Savitt, 1982). Lack of trust of physicians grew during this time since medications and medical treatment provided to Black men and women had atrocious side effects and Blacks were often times exposed to excruciating pain during medical research (Fett, 2002).

Living Blacks were used during treatment for specific health conditions. In one instance, a slave by the name of Fed was placed in a pit with only his head exposed which was then heated to test which medications were effective in preventing heatstroke

(Savitt, 1978). During each trial, Fed was given different medications to test; he would faint and would have to be revived in order to continue with the research study. In other medical testing, Black men, who attempted to run away or who would disobey their owner, were subject to castration (Frazier, 1999). Enslaved Black women were used to search for a cure for vesicovaginal fistula, which is the connective tissue between the bladder and the vagina and causes urinary incontinence (Allen, 1994; Dula, 1994). In addition, the surgical removals of many ailments such as ovarian tumors were perfected on Black slaves (Dula, 1994). There was no anesthesia available during this time period, enslaved women would experience excruciating pain during the surgical operations and could not refuse these experiments since they were considered “property” (Allen, 1994). Slaves were given vaccinations to test its effectiveness prior to the vaccine being offered to Whites (Dula, 1994). These examples along with other medical mistreatments that occurred during slavery were risky, unsafe, and harmful and suggested that Blacks were inferior beings (Dula, 1994).

**Tuskegee syphilis study.** The TSUS is one of the most well-known historical examples of mistreatment that Blacks have experienced in medical research (Freimuth et al., 2001; Gamble, 1997) and is most widely cited as the reason for medical mistrust among Blacks (Byrd & Clayton, 2001; Gamble, 1997; Killien et al., 2000). The United States Public Health Service, along with the collaboration of the Tuskegee Institute, initiated TSUS. The TSUS involved several other agencies, including Macon County Medical Society, Alabama State and Macon County Boards of Health, local Black churches and schools, and Macon County plantation owners (Thomas & Quinn, 1991).

This study was initiated in 1932 in attempts to gather data on the progression of untreated syphilis in Blacks living in Macon County, Alabama (Crenner, 2012). Although this study was initiated because of the recognition of the growing rate of syphilis among Black men and women living in poverty, this study recognized that men played a vital role in the transmission of the disease due to their anatomy (Crenner, 2012). This study lasted for roughly 40 years and involved the deception and denial of treatment for the sole basis of medical knowledge and advancement among Black men in Macon County (Brandon et al., 2005).

During the 40 years of this study, there were a total of 399 Black men who were infected with syphilis (Byrd & Clayton, 2001; Gamble, 1997; Jones, 1992; Williams & Williams, 2011). Researchers lied to participants and informed them that they were being tested for “bad blood,” which during this time was a term used to describe a multitude of illnesses such as anemia, fatigue and syphilis (Byrd & Clayton, 2001; Gamble, 1997; Jones, 1992; Killien et al., 2000). The study also employed Eunice Rivers, a Black nurse from Macon County to have direct contact with participants as a way to build rapport (Thomas & Quinn, 1991). In the 1940s, penicillin was used to treat syphilis, however, the men in TSUS went untreated and were not told that effective treatment was available (Jones, 1992). A few men who were distrustful and questioned the integrity of the study were told not to take penicillin as it was dangerous and could cause more harm than good (Jones, 1992). During the entirety of the TSUS, 28 men directly perished due to syphilis, 100 died due to syphilis-related complications, 40 wives became infected by their significant other, and 19 children had congenital syphilis during birth (Jones, 1992;

Williams & Williams, 2011). The director of venereal disease for the United States Public Health Services indicated that Blacks who participated in TSUS were “not patients” but “subjects” and therefore, the health status of each man did not deserve ethical discussion (Jones, 1992, p 179).

This study has been said to be the essence of deceit, misconduct, and injustice of a healthcare establishments attempts to exterminate Blacks (Corbie-Smith, Thomas, Williams, & Moddy-Ayers, 1999). This may be due to the fact that TSUS is the lengthiest nontherapeutic experimentation of humans in medical history (Thomas & Quinn, 1991). The TSUS has also been labeled as one of the most notorious studies that harmed all participants and sacrificed trust of future medical studies (Crenner, 2012). The TSUS confirms and perpetuates the fears and mistrust that Blacks have had and continue to have towards health care systems and physicians (Gamble, 1997; Thomas & Quinn, 1991). Although the TSUS is not the only cause of mistrust in medical establishments and physicians among the Black community, it has come to symbolize unethical treatments of those who are underprivileged.

**Involuntary sterilization.** In addition to the TSUS, involuntary sterilization serves as another historical example of medical mistreatment in the Black community. In 1939, the “Negro Project” was established by the American Birth Control Federation to decrease the number of careless and catastrophic procreation of Blacks in the South (Patterson, 2009; Randall, 1996). The aim of the project was to establish probationary health facilities that would aid in the reduction of the Black population by sterilizing women, aborting pregnancies, or providing women with birth control (Patterson, 2009).



Many of the public health efforts during the late 1930s were led by eugenicists who were against the reproductive growth of the Black community (Patterson, 2009). The “Negro Project” was funded by the United States government as a way to decrease the rate of birth within the Black community (Randall, 1996).

During the 1960s, the federal government reduced the amount of funding placed on family planning clinics in areas in which a large portion of the population was Black and Hispanic (Dula, 1994). The goal of reduced funding was to decrease the number of individuals, specifically Blacks, on welfare (Randall, 1996). During this time period, Black women experienced involuntary sterilization (Dula, 1994; Roberts, 1997). In attempts to regulate the reproduction of Blacks, sterilization often occurred unbeknownst to the females. Otherwise, females would be told to seek medical treatment and surgery elsewhere (Roberts, 1997). In addition, many doctors refused to provide medical treatment, such as delivering babies, unless the mother would consent to being sterilized after giving birth to her child (Dula, 1994). Sterilization did not only occur in adult women, girls as young as 12 years of age were also sterilized (Dula, 1994). Many parents who were on welfare were deceived into sterilizing their teenage daughters (Dula, 1994). These practices were suspected to have eugenic objectives intended to eradicate Blacks (Dula, 1994). Moreover, if Black women did not agree to sterilization, they were told that they would no longer receive public assistance such as welfare (Roberts, 1997).

**Case review: Henrietta Lacks.** A specific case of medical mistreatment in the Black community occurred with Henrietta Lacks in Baltimore, Maryland in the early 1950s. According to Skloot (2010), Henrietta Lacks was a poor Black female who at age

30 developed stage I cervical cancer. This was the first time that the attending physician at Johns Hopkins had seen cells such as Mrs. Lacks'. Unbeknownst to Mrs. Lacks, samples of her tumor were collected. Although radium treatment was initiated, Mrs. Lacks passed away and at the time of death, she was 31 years of age and left behind five children. The unwitting cells were given to Dr. George Gey, who was interested in finding cells that would live indefinitely outside of the body in hopes to identify the source and cure for cancer. The cells collected from Mrs. Lacks are now known as HeLa cells, abbreviated from Henrietta Lacks. Today, HeLa cells have since been used to develop vaccinations and treatment for many diseases such as polio, Parkinson's disease, herpes, hemophilia, Leukemia, and influenza.

HeLa cells have been used nationally and internationally and have generated millions of dollars in profit. Meanwhile, the Lacks family did not receive compensation, lived in poverty, and had no health insurance. The family did not find out about HeLa cells until 25 years later after the cells were collected, when physicians at Johns Hopkins contacted the Lacks family to obtain blood samples. The family was deceived and believed that they were being tested for cancer when in fact the physicians wanted to learn more about the HeLa cells. Mrs. Lacks' children questioned the motive of the physicians at Johns Hopkins and wondered whether the physicians had killed their mother in order to obtain the cells. Although this is a very specific case, those in the Black community could view the services that Mrs. Lacks received as unethical, shocking, deceitful, and exploitive.

**Case review: Nushawn Williams.** Another case of racial injustice in the medical field is that of Nushawn Williams. According to Shevory (2004), in 1997, a female who tested seropositive for HIV identified Nushawn Williams, a 20-year-old Black male, as one of her sexual partners. Nushawn was notified by a health worker that he was HIV seropositive and he provided the information for several women whom he had sexual encounters; of those 13 were HIV seropositive. At this point in time, public health authorities declared an emergency, determined that Nushawn posed a threat to the health of many individuals, and a judge authorized public health official to waive Nushawn's rights to confidentiality. Nushawn's name and picture were posted on flyers throughout Chautauqua County, New York. The posters indicated that anyone who had sexual intercourse with Nushawn should get tested for HIV.

Nushawn plead guilty to three charges: two for statutory rape and one for reckless endangerment. Nushawn served a 12 years sentence, which ended in 2012; however, a year after serving his sentence, Nushawn is still not a free man due to the civil confinement law. The civil confinement law indicates that anyone who is considered to be unsafe and a dangerous sex offender can be kept out of the community. Shevory (2004) indicates that media played an essential role in the demonization of Nushawn Williams. This continued to perpetuate the stigma and negative stereotypes that Blacks, specifically Black men, are "super predators", "AIDS monsters", or "HIV predators". This insinuates that not only are Black men criminals, but they also spread HIV, and should be treated differently even after being convicted and serving time in the criminal justice system.

**Human immunodeficiency virus.** In the mid-1980s, the accusation that the United States government, specifically the military, created HIV as a bioweapon in Fort Detrick, Maryland, was on the news in India, Soviet Union, Kenya, Senegal, and London (Andrew & Gordievsky, 1990; Sabatier, 1988, United States Department of State, 1987). The United States government requested that these accusations cease, and although international newspapers stopped printing these reports (United States Department of State, 1987), the conspiracy had already reached thousands of individuals and the fear carries on today. This fear existed in the United States, as well as internationally. In South Africa, during the time of apartheid, many Blacks believed that HIV was created by the United States Central Intelligence Agency and Wouter Basson to kill Black South Africans (Niehaus & Jonsson, 2005). Wouter Basson was the director of the apartheid government's biochemical weapons program and was against Black South Africans (Niehaus & Jonsson, 2005).

Throughout the HIV epidemic in the United States, mistrust for health authorities has been a constant theme, especially those who are identified as being “at risk”. Being Black in the United States comes with numerous stereotypes and stigmas, and HIV/AIDS is a highly stigmatized disease. Further shame, silence, and demoralization associated with same-sex intercourse and other secretive sexual behaviors within the Black community, such as being on the down-low, also places increased stigma on those who are HIV seropositive (Goparaju & Warren-Jeanpiere, 2012). Further, the greater likelihood Black men “on the down-low” and the high rates of HIV among the Black community, continues to place heterosexual Black women at increased risk of HIV

infection, which in turn perpetuates the HIV rates among Blacks (Millett, Malebranche, Mason, & Spikes, 2005). Being Black and living with HIV/AIDS can further reinforce stigmatization and discrimination.

The historical and cultural meaning of disease, especially now with HIV drastically affecting Blacks, is essential to understand among the Black community. Medical mistreatments, such as that which occurred during the TSUS, undermines trust that Blacks will have towards public health officials and medical professionals, and explains the development of HIV/AIDS conspiracy beliefs (Thomas & Quinn, 1991). The lack of trust that Blacks have towards physicians and the health care systems and physicians as a whole continues today. As HIV and AIDS continues to grow in the Black community, many Blacks believe that HIV/AIDS is a disease that was created by the American government as a mechanism to exterminate the Black community (Bogart, Galvan, Wagner, & Klein, 2011; Klonoff & Landrine, 1999). This makes intervention, prevention, and care efforts difficult. Given that HIV conspiracy beliefs, a form of medical mistrust, are associated with sexual risk behaviors and lower use of condoms (Bogart & Bird, 2003) and an estimated one in 16 Black men and one in 32 Black women will become infected with HIV (CDC, 2013b), it is imperative to examine factors that affect those who have already been infected with HIV/AIDS.

**HIV and immigration.** The HIV/AIDS, similar to other contagious and communicable diseases, are often treated with unsuccessful and discriminatory strategies by public health officials as attempts to control the disease (Amon & Todrys, 2008). Foreign-born individuals are often held responsible for introducing and transmitting the

diseases to others and in response many foreign-born individuals are secluded, quarantined, and restricted from entering the country (Amon & Todrys; Day, Park, Madras, Gumel, & Wu, 2006). However, these assumptions that foreign-born individuals are responsible for introducing HIV are often false and not scientifically based (Nieburg et al., 2007).

On July 9<sup>th</sup>, 1982, the CDC published that 34 cases of AIDS was found among Haitians living in five states (CDC, 1982a). Haitians were identified as one of the four high-risk groups for contracting AIDS (Chavez, 2012). It was not until 1990 that Haitians were removed from this list (Marc et al., 2010). In May 1987, the Public Health Services added AIDS to the list of “dangerous contagious diseases”, which prevented foreign-born individuals from entering the United States unless waivers were obtained (CDC, 2009; Nieburg et al., 2007). Previously, all individuals who applied for visas were to receive mandatory HIV testing (CDC, 2009; Nieburg, Morrison, Hofler, & Gayle, 2007). Following this regulation, foreign-born individuals were prevented from obtaining permanent immigration status if they were HIV seropositive (CDC, 2009). The placement of HIV/AIDS on the “dangerous and contagious disease” list was based on misinformation and stigma associated with HIV/AIDS. The Title 42 Code of the Federal Regulations, Part 34 under section 212(a)(1) of the Immigration and Nationality Act states that any foreign-born individual who is determined to have a “communicable disease of public health significance” is prohibited from entering the United States and ineligible for a visa (Nieburg et al., 2007).

The discovery of HIV was not the only purpose for placing this ban; the growing number of foreign-born individuals increased fear among Americans (Fairchild & Tynan, 1994). Fear resulted in all foreign-born individuals entering the United States as being labeled with having their own unique “immigrant diseases” (Fairchild & Tynan, 1994). Lack of knowledge associated with HIV/AIDS lead many individuals to fear that foreigners were bringing the virus into the country. This policy was put into place to protect native-born individuals from contracting the disease; ironically, at the time, there were more known cases of HIV/AIDS in the United States than internationally (Nieburg et al., 2007).

An example of the exclusionary practices of the United States government towards foreign-born HIV seropositive individuals is that of the Haitian refugees at Guantanamo Bay (White, 2007). Haitians were identified as being at high risk for contracting AIDS due to the “4-H Club” which identified homosexuals, Haitians, hemophiliacs, and heroin users as being at risk (Chavez, 2012). In 1991, many Haitians were fleeing to the United States to seek asylum (Chavez, 2012). These attempts often failed as evidenced by the numerous individuals who lost their lives at seas and whose bodies washed ashore the beaches in Florida (Marc et al., 2010). For those not lost at sea, many were sent to immigration camps (Marc et al., 2010). The United States Naval Base, Camp Bulkeley, became home to roughly 300 Haitians. Many Haitians seeking freedom from their political persecution were now detained (Chavez, 2012). While many Haitians were escorted to the United States, several were detained because they were HIV seropositive (Chavez, 2012).

The conditions at Guantanamo Bay were shared during the June 8, 1993 trial in which Judge Sterling Johnson indicated that individuals residing at Guantanamo Bay were surrounded by barbed chains, had only cots to sleep on, and were guarded by military since they were not permitted to leave the premises (Qureshi, 1995). Many Haitians were treated like convicts and were subject to military inspections as they slept (Qureshi, 1995). Accusers, such as Gilbert et al. (2007) indicate that Haitians played an essential role in introducing the HIV/AIDS to the United States. The researchers continue to suggest that HIV moved from Africa to Haiti in the mid-1960s, spread throughout Haiti, before spreading throughout the world to include the United States in the late 1960s, early 1970s. Although few researchers imply that HIV was in fact introduced into the United States by Haitians (Gilbert et al., 2007), many other studies have indicated that the policy that were set in place were created with minimal knowledge of HIV and fear (Fairchild & Tynan, 1994; Nieburg et al., 2007).

Although Haitians were targeted as introducing HIV into the United States, research suggests otherwise (Auerbach, Darrow, Jaffe, & Curran, 1984; CDC, 1982b). The CDC conducted a cluster study in 1982 in the attempt to understand the complex factors that placed Haitian's, heroin users, hemophiliacs, and homosexuals at higher risk for contracting HIV. The purpose of the CDC cluster study was to examine the sexual network of the first cluster of HIV seropositive individual's in California and identify the original source of HIV. "Patient 0" a "non-Californian with [Kaposi's Sarcoma]" was identified as this original source (CDC, 1982b). Further studies showed that "patient 0" was at the center of the sexual network diagram, which involved 40 men in roughly 10



cities in the United States, and possibly the original source of introducing HIV into the United States (Auerbach, Darrow, Jaffe, & Curran, 1984). The identity of “patient 0” was uncovered by Randy Shilts, author of *And the Band Played On*, as Gaëtan Dugas a flight attendant from Canada (Shilts, 1987).

Regardless of the study that linked “patient 0” at the center of the HIV sexual network (Auerbach et al., 1984), Haitians continued to be identified as introducing HIV and restricted from entering the United States (Gilbert et al., 2007; Nieburg et al., 2007). The restriction of entry into the United States by HIV seropositive foreign-born individuals stayed in effect for roughly 22 years. It was not until 2010, under President Obama’s administration, that the travel restriction was lifted allowing HIV seropositive individuals entrance into the United States (U. S. Department of Health and Human Services, 2009).

In summary, from a historical perspective, Blacks in the United States have experienced medical cruelty and injustices stemming from slavery, TSUS, involuntary sterilization, and most recently, the case regarding Nushawn Williams, to name a few. Further, foreign-born individuals have also experienced mistreatments and have been blamed for introducing HIV into the United States. The next section will discuss the literature on medical mistrust, followed by mistrust amongst the Black community, Blacks living with HIV, and nativity differences. Lastly, the role of spirituality/religiosity, racial pride, patient-physician communication and the impact each has on trust will be reviewed. The detailed description of the quantitative, qualitative, and measurement studies are discussed.

## Literature Search Procedure

Included in this literature review are studies selected through a comprehensive search of available literature. Search on medical mistrust among Blacks, Blacks living with HIV/AIDS, and nativity differences were included. The researcher employed a computerized search of the following databases: PsycINFO, ERIC, Education Research Complete, Medline, Dissertations Abstracts, Social Science Citation Index, and Dissertation and Thesis Full Text. Keywords used in the search included a combination of the following words: medical mistrust, Black, African American, medical distrust, trust, racial pride, patient-physician relationship, communication, HIV/AIDS, nativity, religion, religiosity, spirituality, refugee, immigrant, and foreign-born. A breakdown of the research articles and the keywords addressed are provided (see Table 1).

Table 1

*Approaches to Describing Race/Ethnicity, HIV and Nativity in the Medical Mistrust Literature*

Author (year)	Race/ethnicity term used	HIV	Nativity	Medical Mistrust
Bogart et al. (2004)	African American			
Boulware et al. (2003)	African American, Black			✓
Halbert et al. (2006)	African American			✓
LaVeist et al. (2000)	African American			✓
O'Malley et al. (2004)	African American			✓
Thompson et al. (2004)	African American			✓

(continued)

<b>Author (year)</b>	<b>Race/ethnicity term used</b>	<b>HIV</b>	<b>Nativity</b>	<b>Medical Mistrust</b>
Armstrong et al. (2008)	Black		✓ Parents but not individual	✓
Casagrande et al. (2007)	African American, Black			✓
Brandon et al. (2005)	African American, Black			✓
Gamble (1997)	African American	✓		✓
Halbert et al. (2009)	African American			✓
LaVeist et al. (2009)	African American, Black			✓
Benkert et al (2006)	African American		✓ Demographic gathering only	✓
Zekeri et al. (2006)	African American			✓
Corbie-Smith et al (2002)	African American			✓
Castillo et al., (2012)	African American, Black			✓
Winston et al. (2004)	African American, Black	✓		✓
Russell et al. (2012)	African American, Blacks			✓
Thompson et al. (2003)	African American		✓ Demographic gathering only	✓
Shelton et al. (2011)	African American, Black		✓	✓
Hammond (2010)	African American			✓
Hoyt et al. (2012)	African American, Black	✓		✓
Ravenell et al. (2008)	African American	✓		✓
Suite et al. (2007)	African American, Black			✓
Mosley et al. (2007)	African American			✓
Thomas & Quinn (1991)	African American, Black	✓		✓

(continued)

<b>Author (year)</b>	<b>Race/ethnicity term used</b>	<b>HIV</b>	<b>Nativity</b>	<b>Medical Mistrust</b>
Prosser et al. (2012)	African American, Black	✓	✓ (born outside of U.S.)	
Shippee et al. (2013)	African American, Black		✓ (born outside of U.S.)	✓
Armstrong et al. (2006)	African American			✓
Lynn-McHale et al (2000)	African Americans not mentioned			✓
Jennings et al (2003)	African Americans not mentioned	✓		✓
Klonoff et al. (1999)	African American, Black	✓		✓
Bogart et al. (2005)	African American, Black	✓		✓
Garber et al. (2007)	African American, Black, African, Caribbean-American	✓		✓
Moutsiakis & Chin (2007)	African American, Black	✓		✓
Slomka et al. (2008)	African American	✓		✓
Saha et al. (2010)	African American	✓		✓
Weintrob et al (2009)	African American, Black	✓		
Bogart et al. (2010)	African American	✓		✓
Thrasher et al. (2008)	African American	✓		✓
Sohler et al. (2007)	African American, Black	✓	✓ Place of birth	✓
Bogart et al. (2011)	African American, Black	✓		✓
Bohnert et al. (2009)	African American, Black	✓		✓
Gaston and Alleyne-Green (2013)	African American	✓		✓

## **Review of Medical Mistrust Literature**

Through these exhaustive efforts to comprehend whether medical mistrust influences HIV seropositive racial/ethnic minority groups, specifically Blacks, the impact of nativity has been virtually unaddressed (see Table 1). Although research has been reluctant to address nativity differences, within the United States since the 2009 HIV/AIDS travel restriction has been lifted (U. S. Department of Health and Human Services, 2009), there are now large groups of HIV seropositive foreign-born individuals living in the United States (Prosser, Tang, & Hall, 2012), which should stimulate renewed attention to foreign-born individuals' potential distinct difference in medical mistrust and HIV-related services. The few peer reviewed research articles, seven within this literature review, that have gathered information regarding the place of birth or nativity status, many only do so for demographic purposes and do not disaggregate the data and conduct statistical analysis to determine whether the differences obtained within each study is due to nativity differences. Of the seven articles that gather information on place of birth for each participant, only one addresses HIV and medical mistrust (Sohler, Fitzpatrick, Lindsay, Anastos, & Cunningham, 2007). The few articles that examine nativity differences will be discussed in detail.

It is important to note that race and ethnicity solely are not risk factors for acquiring or transmitting HIV (CDC, 2007). Complexities associated with historical, sociopolitical, organizational, environmental, and cultural factors places Blacks at a higher risk of contracting HIV (CDC, 2007). Specific cultural factors include racism,

discrimination, and historical factors such as slavery and the TSUS (Byrd & Clayton, 2002; Casagrande, Gary, LaVeist, Gaskin, & Cooper, 2007; Gamble, 1997).

**Medical mistrust and Blacks in the United States.** Medical mistrust is frequently cited as a factor that contributes to racial and ethnic disparities within the health care system (Boulware et al., 2003; Halbert et al., 2006; LaVeist et al., 2000) and, often prevents racial and ethnic minorities from seeking medical services (LaVeist et al., 2000; O'Malley et al., 2004; Thompson et al., 2004). Among the general United States population, mistrust is relatively high (Armstrong et al., 2008; LaVeist et al., 2000), however, it is ingrained within the Black community due to the historical discrimination, racism, and medical mistreatments that Blacks have experienced (Boulware et al., 2003; LaVeist et al., 2000). Specifically, Casagrande and colleagues (2007) determined that perceived discrimination in Blacks is associated with delays in seeking medical treatment and adherence to medical recommendations.

One study in particular conducted by Brandon, Isaac, Thomas, and LaVeist (2005) investigated whether there were racial differences in knowledge about the TSUS. The results of this study found no statistically significant racial difference in the knowledge of the TSUS and no indication that knowledge of the TSUS predicted medical mistrust. However, Blacks held higher levels of medical mistrust compared to their White counterparts. This study indicated that most individuals were unaware of the TSUS and cast doubt on the notion that Blacks have higher levels of medical mistrust due to the Tuskegee Syphilis. The study concluded that there are other experiences (personal and/or historical) that could impact racial differences in medical mistrust which contradicts prior

research suggesting that the TSUS contributes to the higher levels of medical mistrust among Blacks (Gamble, 1997).

Halbert et al. (2009) indicate that trust is a factor that is impacted by race and exposure to healthcare providers. According to LaVeist, Isaac, and Williams (2009), trust may reflect the individual's expectations of unjust treatment and perceived lack of support from the medical professional, based on negative perceptions of medical services. Medical mistrust amongst Blacks has been linked to medical mistreatment and slavery (Byrd & Clayton, 2002; Fett, 2002; Gamble, 1997).

Benkert, Peters, Clark, and colleagues (2006) tested Perceptions of Racism and Mistrust in Health Care theory among low-income Black adult patients who were currently receiving services from a clinic. This theory indicated that racism that is perceived affects cultural mistrust, which then affects trust in providers; all three aspects affect satisfaction with services received by a medical provider. Amongst the group of low-income Blacks surveyed, the results conveyed that perceptions of discrimination, prejudice, racism and mistrust of Whites had significant adverse effects on trust and satisfaction towards medical providers. Higher rates of perceived racism resulted in lower satisfaction and vice versa. Furthermore, the perception of racism had negative effects on satisfaction, which were moderated by cultural mistrust and trust in providers. That is, those with high levels of perceived racism had low levels of satisfaction indicating a linear relationship between perceived racism and satisfaction. In addition, the level of cultural mistrust and trust in provider also influenced the level of satisfaction that an individual held towards his or her provider. Benkert and colleagues suggested that

enhancing health outcomes for Blacks requires an extensive comprehension of cultural competence and sensitivity that tackles discrimination, prejudice, and racism and its effects on the patient-provider relationships.

In an effort to further understand health disparities among ethnic and racial minorities, Zekeri and Habtemariam (2006) examined psychosocial factors that influenced health disparities among Black college students in Alabama. Many Black college students in this study cited that medical mistrust, mistrust of Whites, racism, discrimination, poverty, and concerns related to health insurance as factors that impact racial disparities in health. This study concluded that efforts to decrease health disparities should focus on rural areas, specifically those with high poverty levels. Since race may be used in research as a proxy for socioeconomic status, if there are true differences in medical mistrust due to race, the impact of socioeconomic status may need to be investigated further as a separate demographic variable (Corbie-Smith, Thomas, & St. George, 2002).

A study conducted by Armstrong and colleagues (2008) investigated whether racial differences in medical mistrust are closely tied to one of the two domains: values (honesty, respect, and confidentiality) or technical competence (skill, proficiency, and aptitude). After adjusting for socioeconomic status, health/psychological status, and health care access, Blacks had significantly lower levels of values distrust but not for competence distrust compared to their White counterparts. Armstrong and colleagues indicate that the racial disparities associated with values distrust and competence distrust explains the mixed results of race and medical distrust overall within the literature.



Although place of birth was gathered in this study, it was only gathered amongst the participants' parents place of birth and not the individuals participating in the study.

Regardless of the type of service being rendered, whether it is to address prostate cancer (Halbert et al., 2009; Pedersen, Armes, & Ream, 2012) or clinical research (Castillo, Jandorf, Thelemaque, King, & Duhamel, 2012), Blacks tend to have higher levels of mistrust which prevents them from accessing and participating in services. Research has shown that Blacks experiences of medical mistrust have impacted their utilization of various medical care systems such as hospice and palliative care (Winston, Leshner, Kramer, & Allen, 2004) as well as organ donations (Russell, Robinson, Thompson, Perryman, & Arriola, 2012). Winston and colleagues suggested that increasing culturally competent and sensitive professionals, including spiritual leaders, and funding could promote access to various healthcare services. Further, professionals and agencies should recognize the effects of race, culture, and issues related to being in a minority status in order to put policies and practices in place that decrease insensitivity among racial and ethnic minorities (Winston et al., 2004).

Both Black women and men report higher levels of medical mistrust compared to their White and Latino/a counterparts (Thompson, Valdimarsdottir, Jandorf, & Redd, 2003). Research shows that Black women tend to report higher levels of medical mistrust in genetic testing (Thompson, Valdimarsdottir, Jandorf, & Redd, 2003), breast cancer screenings (Thompson et al., 2004), and medical mistrust played a role in medication adherence (Shelton, Goldman, Emmons, Sorensen, & Allen, 2011). Whereas mistrust of healthcare organizations by Black men is related to previous negative social/healthcare

experiences, personal characteristics, expectations of being treated differently solely based on race (Hammond, 2010), higher levels of systematic discrimination and conspiracy beliefs (Hoyt, Nemeroff, Huebner, Rubin, Lee, & Jean, 2012) and lower levels of HIV testing (Hoyt et al., 2012). Further, Ravenell, Whitaker, and Johnson (2008) identified lack of awareness of one's health, fear, financial constraints, cultural differences, and medical mistrust barriers to accessing healthcare for Black men.

Previous research indicates that mistrust is a factor for seeking treatment not only in medical organizations, but mental health organizations as well. A study by Suite, La Bril, Prim, and Harrison-Ross (2007) explored the association between historical experiences and the effect that it has on contributing to mistrust among Blacks. This study conducted a literature review on racism, medical mistrust, among Blacks and concluded that a practitioner's failure to examine the broader historical context in which perceptions, assumptions, and beliefs are derived from contribute to the mistrust in both the medical and mental health fields. This lack of further review beyond the clinical history gathering phase continues to perpetuate medical mistrust and health disparities among people of color, specifically Blacks.

In conclusion, medical mistrust within the Black community is of significant concern. Mistrust within the community leads Blacks to be less likely to participate in medical trials, interventions, and seek counseling services (Mosley, Freed, Bullard, & Goold, 2007). This mistrust can further perpetuate the cycle of inadequate services and interaction with medical professionals that Blacks currently experience. Given the high rates of HIV in Blacks, it is imperative that public health officials and medical

professionals realize that the HIV/AIDS conspiracy belief and medical mistrust is legitimate and is an attitudinal barrier to effective medical services that Blacks receive (Thomas & Quinn, 1991).

**Blacks and nativity.** According to the United States Census Bureau (2010) 13% of the United States population is foreign-born; this includes naturalized citizens, students, refugees, and undocumented immigrants. Foreign-born individuals increase the number of ethnic and racial minorities in the United States. More specifically, within the state of Virginia, approximately 11% are foreign-born (United States Census Bureau, 2013c). There are approximately 21,000 people living with HIV/AIDS in 2009, which is roughly one in every 380 Virginian (Virginia Department of Health, 2010). Among every five persons in Virginia living with HIV/AIDS, approximately three are Black (Virginia Department of Health, 2010). Blacks make up roughly 20% of the population in Virginia and account for 62% of the HIV seropositive individuals living with HIV/AIDS (Virginia Department of Health, 2010); this is higher than the national average of 44% (CDC, 2011a). Although 95% of persons living with HIV live outside of the United States (Joint United Nations Programme on HIV/AIDS, 2010), understanding HIV in foreign-born persons who are currently residing in the United States allows for a better understanding of HIV and those that it directly affects.

A few researchers have examined the differences between native-born and foreign-born Blacks living with HIV/AIDS in the United States. One study in particular conducted by Prosser, Tang, and Hall (2012) aimed at describing the epidemiology of HIV among native and foreign-born persons living with HIV. Data for this study were

acquired from the National HIV Surveillance System, which accumulates data from local and state organizations, and is controlled by the CDC. Demographics, geographical locations, and risk factors of foreign-born persons with HIV diagnosis while living in the United States (to include 46 states) and 5 United States territories were reported. The results indicated that, of the 191,697 individuals diagnosed with HIV between 2007 and 2010, roughly 16.2% or 30,995 individuals were foreign-born. Of those whose country of birth were provided, 14.5% were from Africa, 41.0% were from Central America and Mexico, and 21.5% were from the Caribbean. This study concluded that there are divergent epidemiologic characteristics among native and foreign-born people within the United States. Specifically, foreign-born individuals born in Africa were more likely to have higher rates of infection among women and children and those born in Africa or in the Caribbean were more likely to have contracted HIV through heterosexual contact.

A study by Shippee and colleagues (2013) assessed the association between nativity among racial and ethnic discrimination in medical setting, distrust, and attitudes towards complementary and alternative medicine. Complementary and alternative medicine as an alternative to traditional medicine is viewed as a way for minorities to avoid unjust treatment that may occur in traditional medicine. Such examples of complementary and alternative medicine are mind and body medicine as well as energy medicine. The results showed that those who were foreign-born had higher rates of distrust in traditional medicine and optimistic attitudes about complementary and alternative medicine in publicly insured adults. This study concluded that positive

attitudes toward alternative medicine may be due to distrust and marginalization that occurs in traditional medicine.

**Medical mistrust, Blacks, and HIV.** Trust in the medical field has decreased and this decrease can be explained by a lack of access to health care, discrimination, malpractice, unethical treatment and concerns with confidentiality (Armstrong et al., 2006). Technological advancement has resulted in medical mistrust becoming more visible and due to this, may make diminishing medical mistrust extremely difficult (Lynn-McHale & Deatrick, 2000). Mistrust among Blacks has been considered to be a source of racial disparities in HIV care. Racial and ethnic differences in medical mistrust shifted to medical mistrust among Blacks living with HIV during a time in which HIV was rapidly affecting this population (Jennings & Anderson, 2003). HIV/AIDS related medical mistrust began during the first few years in which the HIV epidemic emerged (Jennings & Anderson, 2003). A significant amount of research have identified that Blacks believe that HIV is a virus that was created by the government as a way to control the Black population (Klonoff & Landrine, 1999; Bogart & Thorburn, 2005). Medical mistrust coincided with the progressions in medical treatment. Improvements in HIV testing, treatment, and care has the possibility to decrease the rate of HIV in the United States (CDC, 2013c), however, the rise in medical mistrust has the potential to negate any medical progression made due to the growing number of those who refuse to participate in biomedical research (Garber, Hanusa, Switzer, Mellors, & Arnold, 2007).

Blacks continue to be underrepresented in studies that aim to understand the effectiveness of HIV-related treatment. Garber, Hanusa, Switzer, Mellors, and Arnold

(2007) examined attitudes, concerns, and participation related to HIV treatment trials among HIV seropositive Blacks. Results implied that more than half (57%) of participants had previously been asked to participate in HIV treatment trials, and of those 86% participated. In addition, medical trust/distrust did not affect participants' willingness to partake in future HIV treatment trials. This study concluded that HIV seropositive Blacks who are currently receiving HIV treatment should be asked to participate in treatment trial studies.

Although, Blacks continue to be disproportionately affected by this virus, many do not participate in vaccine trial research (Moutsiakos & Chin, 2007). To understand why Blacks do not participate in HIV vaccine research, Moutsiakos and Chin (2007) conducted 11 ethnographic interviews on Blacks living with HIV in an urban area. Two groups were examined, those who were currently participating in clinical trials and those who were not. The results from this study found that medical mistrust (Slomka, Ratliff, McCurdy, Timpson, & Williams, 2008), stigma associated with HIV, and misinformation about HIV were factors that influenced nonparticipation in clinical trials (Moutsiakos & Chin, 2007). Moutsiakos and Chin conclude in stating that destigmatizing HIV and properly educating the Black community about HIV should occur individuals who are HIV seropositive spend with their physicians receiving HIV-related treatment in order to increase trust within the Black community.

Blacks who reported having lower levels of trust for their HIV treatment provider, were less likely to receive antiretroviral medications even when they were eligible to receive treatment, were less likely to adhere to medication regimen, and to have

suppressed viral loads (Saha, Jacobs, Moore, & Beach, 2010; Weintrob et al., 2009). To understand factors that may influence adherence to antiretroviral medications, Bogart, Wagner, Galvan, and Banks (2010) conducted a study to understand the relationship between HIV conspiracy beliefs and nonadherence to antiretroviral medication among Black men living with HIV. Information on HIV conspiracy beliefs, demographic characteristics, mental health, and substance use were gathered, and the Medication Event Monitoring System monitored medication adherence. Results showed that those who scored high on both subscales (genocidal and treatment related beliefs) had lower treatment adherence suggested that future interventions should target HIV conspiracy beliefs, especially treatment mistrust beliefs among Black HIV seropositive men.

Thrasher, Earp, Golin, and Zimmer (2008) found that racial minorities who experienced discrimination predicted higher levels of distrust, which in turn decreased the benefits that one thought they would receive during treatment, and lowered medication adherence.

Furthermore, the race of a physician may influence a patient's trust of the physician in the patient-physician relationship. Sohler and colleagues (2007) examined whether being the same race of the physician would affect medical mistrust at the system level and interpersonal level among racial and ethnic minority men living with HIV. Data were collected using the Audio Computer-Assisted Self Interview that read each question aloud for each participant. 84.7% of participants were born in the United States while the remaining 15.3% were born outside of the United States. This study found that physician's race did not affect trust at the interpersonal level but lowered mistrust at the system level. That is, being the same race of one's physician lowered the level of mistrust

towards the health care system, but did not increase the level of trust toward the individual's physician. In order to assist patients in navigating the health care system and potentially increase health outcomes, there should be racial and ethnic concordance between patient and provider.

A study conducted by Bogart, Galvan, Wagner, and Klein (2011), aimed to understand the relationship between the HIV conspiracy belief and sexual risk taking among Black men in the Los Angeles California area. These interviews gathered information on conspiracy beliefs, sexual behaviors, and demographic characteristics. The results showed that 54% of Black males who reported higher levels of HIV conspiracy beliefs also reported engaging in unprotected sex. A cultural element that may influence Blacks' sexual risk and consequently the acquisition and transmission of HIV is medical mistrust for medical services, professionals, and the preventative messages sent by these medical officials (Bogart et al., 2005). Bogart et al. (2011) concluded that secondary prevention efforts, prevention efforts after the disease has occurred, should target medical mistrust as a factor that contributes to sexual risk taking behaviors among HIV positive men. On the contrary, Bohnert and Latkin (2009) examined the relationship between HIV serostatus testing and HIV conspiracy beliefs in Blacks. This study showed that those who never had an HIV test had higher rates of conspiracy beliefs.

Gaston and Alleyne-Green (2013) conducted a literature review to understand the impact of Blacks' beliefs about HIV medical care on treatment adherence. The authors reviewed 16 peer-reviewed descriptive studies, which conveyed that racism, conspiracy beliefs, and patient provider relationship impacted engagement. This study concluded that



medical providers should take time to listen to narratives expressed by patient, openly communicate treatment decision, and explore beliefs that negatively influence treatment decisions.

The review of the medical mistrust literature examined how medical mistrust is established, the influences that mistrust has on healthcare decisions within the Black HIV seropositive community, and nativity differences amongst Blacks living with HIV/AIDS. The next section discusses spirituality and religion and the importance of spirituality within the Black community. Research has implied that beliefs and values associated with religiosity and spirituality are linked with trust among ethnic and racial minorities (Tarn et al., 2005). Therefore, understanding the potential linkages between mistrust and spirituality/religion could be beneficial when attempting to understand trust (or lack thereof) within the healthcare system and establishing effective potential intervention and prevention approaches.

**Spirituality/religion.** Individuals who are diagnosed with a life-altering disease such as HIV/AIDS often have changes to their perspectives on life (Idler, 1995). As a way to deal with the life altering disease, many individuals turn to spirituality and personal support (Idler). Religiosity, a concept related to religion, involves the emotional, behavioral, intellectual, relational, and physical processes connecting religion and spirituality (Miller & Thoresen, 2003). The term spirituality is a more individual, subjective element of religious experiences and the literature implies that both spirituality and religion are entwined (Miller & Thoresen). The interconnection between spirituality and religion is often referred to as spirituality/religion (Szaflarski et al., 2006).

Examining religion and spirituality within the Black community is essential because the church is the central institution and is financially controlled, primarily, by the Black community (Miller, 2005). Black churches have served as a space in which discussions about oppression and mistreatment could be held; this dates back to slavery (Moore et al., 2012). Black churches, historically, have served as the core of Black politics (King, Burgess, Akinyela, Counts-Spriggs, & Parker, 2006), social activities within the Black community (Baumeister & Leary, 1995), and provide a network for emotion and physical support and is a resource for those to cope (Miller, 2005). Many Blacks have a religious perspective or orientation that is ingrained in the Black cultural history (Eiser & Ellis, 2007).

When facing a serious illness, many individuals rely on resources such as community involvement, privately focused religious devotion, and religious practices (Pargament et al., 2004). Spirituality and religion have been identified as ways in which those living with HIV cope with their illness (Fryback & Reinert, 1999; Miller & Thoresen, 2003). On the contrary, religion and spirituality have been used to explain the development of HIV. Bryan (1990) specifically found that many individuals believe that AIDS was created by God to punish those who were engaging in sacrilegious practices and that AIDS is a way to punish those for their sins.

Spirituality and religion have been linked with improving mental health and physical symptoms amongst those living with chronic health illnesses (Miller & Thoresen, 2003). A high sense of religiosity has been linked with high levels of health seeking behaviors (Albaugh, 2003; Seeman, Dubin, & Seeman, 2003). Often times,

religion has been identified as a protective factor for health implications (Rostosky, Danner, & Riggle, 2010) and connection between hopelessness and meaningfulness among individuals living with HIV/AIDS (Fryback & Reinert, 1999). Spirituality among individuals living with HIV/AIDS has been shown to prolong HIV related survival (Ironson, Stuetzle, & Fletcher, 2006).

A majority of the research on religiosity and spirituality has been on healthy individuals. Ironson, Stuetzle, and Fletcher (2006) wanted to determine whether changes in spirituality/religion predict disease progression among HIV seropositive individuals. The study examined spirituality and religiosity prior to and after one was diagnosed with HIV over a period of 4 years. Data were collected through interviews and questionnaires and results of this study showed that 45% of individuals experienced an increase in spirituality/religion once they were told they were HIV positive compared to 42% who had no change in spirituality/religion. Further, those who reported an increase in spirituality/religion after their diagnosis had significantly lower viral load and better preservation of their CD4 cells over a 4-year period. This study concluded in stating that an increase in spirituality and/or religiosity after one is diagnosed with HIV predicts HIV disease progression, specifically slowing the rate of the disease.

Among those living with HIV/AIDS, many ethnic and racial minorities report greater use of spirituality/religion as a way to cope (Pargament et al., 2004). Of those living in the United States who are HIV seropositive, 85% confirm the importance of spirituality within their lives (Lorenz et al., 2005). Spirituality is often used as a way to cope with concerns related to death, loss, hope, and grief for people living with

HIV/AIDS (Siegel & Schrimshaw, 2002). Spirituality is an aspect that gives purpose to one's life, especially when approaching the end of life (Lo et al., 2002). Among individuals who are HIV seropositive, higher levels of spirituality has been linked with high overall quality of life, well-being, and satisfaction with one's life (Tsevat et al., 1999; Pargament et al., 2004).

Lorenz et al. (2005) aimed to describe the factors associated with importance in religiosity and spirituality among HIV seropositive individuals. A total of 2,266 HIV seropositive individuals participated in this longitudinal study between the years of 1996 and 1998. Participants were randomly selected from the HIV Cost and Services Utilization Study throughout the United States. Data were collected through interviews and a survey. The results of this study showed that roughly 90% of respondents felt that spirituality was important in their lives, approximately 70% felt that religion was an important aspect of their life, 72% relied on their spirituality or religion to make decisions, and 65% used religion to address their problems. Individuals who resided in areas other than the western parts of the United States had higher levels of religiousness. This study concluded that religiosity and spirituality is more important among individuals living with HIV compared to the general population.

Tsevat and colleagues (1999) found that 49% of HIV seropositive patients reported a better spiritual life after they had contracted HIV/AIDS, compared to only 29% who reported that their life was worse than it was prior to being diagnosed with HIV/AIDS. A study conducted by Cotton and colleagues (2006), they found that 75% of HIV seropositive individuals reported that their illness slightly improved their faith.

Specifically, this study found that ethnic and racial minorities tended to be more spiritual and reported higher levels of life satisfaction and self-esteem (Cotton et al., 2006). The utilization of spirituality and optimistic religious coping approaches has been correlated with a reduction in mortality and spiritual growth (Pargament, Ensing, & Falgout, 1990; Zuckerman, Kasl, & Ostfeld, 1984) as well as an increase in endorsing safer sex practices (Corbin, Voisin, & Snell, 2009).

In an extension of the Tsevat and colleagues (1999) study, Szaflarski and colleagues (2006) investigated the effects of spirituality/religion on the opinions of those who were HIV seropositive and to establish a conceptual model of spirituality/religion and the quality of life among HIV seropositive patients. The relationship between spirituality/religion, life improvement since HIV/AIDS diagnosis, social support, self-esteem, healthy beliefs, and health status were examined using a path analyses. The results depicted that having an optimistic outlook had the largest effect on one feeling that his or her life had improved. Furthermore, a feeling that ones life had improved was directly related to spirituality/religion (30%) and indirectly due to spirituality/religion (39%). This study concluded that spirituality/religion is both directly and indirectly associated with one feeling that his or her life is better currently than it was previously.

The data collected in Tsevat and colleagues' (1999) study were further examined by Cotton and colleagues (2009) to describe the racial differences in spirituality/religion among HIV seropositive individuals. Demographic and clinical variables were examined. The results of this study showed that fewer Blacks felt alienated from their religious communities (21%) compared to their White counterpart (44%). In addition, 52% of

Blacks reported becoming more spiritual since being diagnosed with HIV/AIDS. This study concluded that medical professionals should be aware of the changes in religiosity and spirituality associated with HIV/AIDS in Blacks because it is linked with optimism, an attribute that can be useful when coping with terminal illnesses, as well as improved health outcomes, such as fewer health risk behaviors.

Research has implied that beliefs and values associated with religiosity and spirituality are linked with trust among ethnic and racial minorities (Tarn et al., 2005). However, little is currently known about the association between mistrust and spirituality/religion among native and foreign-born Blacks living with HIV/AIDS and further research is warranted. Another variable that may provide important insight into the medical mistrust that Blacks hold is racial pride since those with higher levels of racial pride also hold higher levels of medical mistrust (Shelton et al., 2010). The next section will address racial pride within the Black community. Thorough discussion of research studies that examine the association of racial pride and mistrust will be provided.

**Racial pride.** The experiences of Blacks in the United States are uniquely different than that of other racial and ethnic groups (Sellers, Smith, Shelton, Rowley, & Chavous, 1998). Blacks, unlike other racial groups, have had their rights as human beings rejected by the United States Constitution (Sellers et al., 1998). Although Blacks are not the only racial group in the United States to experience slavery, Blacks were legally considered property. As a historically oppressed group, identity formation for Blacks occurs through making sense of a world ruled by Whites (Phelps, Taylor, Gerard, 2001). Race is an essential part of the Black community (Seller et al., 1998).

Race incorporates both customary African and Black American cultures and plays a role in identity formation (Seller et al., 1998). However, this concept does not allow for variation within the Black race to portray cultural differences such as experiences, attitudes, rituals, religion, and communication (Seller et al., 1998). It is imperative to recognize that Black people in the United States come from various regions around the world and that racial pride may vary from individual to individual.

Racial pride is defined as the meaning that individuals attach to their racial group membership and it has been shown to increase receipt and acceptance of health engagement efforts (Landrine & Klonoff, 1995). As previously noted, mistrust of the medical community is deeply rooted in the Black community. The TSUS is frequently cited as the source of this mistrust which may play a role in health care disparities (Gamble, 1997). One factor contributing to health disparities is that roughly 3.5% of physicians in the United States are Black, and a smaller proportion of Black physicians treat people living with HIV/AIDS (American Medical Association, 2010), whereas Blacks make up roughly 13.1% of the United States population, this indicates that a majority of Blacks will see a physician who is not Black (United States Census Bureau, 2013a). Racial concordance between the patient and the physician was correlated with higher levels of satisfaction and participation (Cooper-Patrick et al., 1999).

To examine the psychometric properties of the group-based medical mistrust scale, Shelton et al. (2010) tested the validity of the construct by investigating the correlation between avoidance with health care services, racial identity, and group-based medical mistrust on a sample of Black men. This study found that those who had stronger

identification with the Black racial group had higher levels of group based medical mistrust. The group-based medical mistrust is distinctively different than other mistrust scales in that it focuses on racism and discrimination provided by health care establishment.

Benkert, Hollie, Nordstrom and colleagues (2009) conducted a study to investigate the associations between cultural mistrust, medical mistrust, and racial identity and to predict patient's satisfaction amongst Blacks receiving services from a nurse practitioner. Results indicate that the participants were satisfied and trusted the nurse practitioner, although they held moderate levels of mistrust of Whites and the healthcare system. Specifically, Black men with lower racial identity attitudes were less likely to be satisfied with services delivered by their primary care nurse. This study concluded that Black participants' racial identity attitudes and the relationship held between the patient and provider had significant effects on satisfaction. However, this study did not examine the association between cultural mistrust, medical mistrust, and racial identity to predict satisfaction among HIV seropositive patients.

A few studies have examined the relationship between racial identity and cultural mistrust (Phelps, Taylor, & Gerard, 2001; Townes, Chavez-Korell, & Cunningham, 2009). These studies have found that those with high racial identity attitudes also have high levels of cultural mistrust. That is, those who strongly identify with being Black also had higher cultural mistrust. Cultural mistrust is "...the belief acquired by [Blacks], due to past and ongoing mistreatment related to being a member of that ethnic group, that Whites cannot be trusted" (Terrell, Taylor, Menzise, & Barrett, 2009, p. 299). Medical



mistrust is the lack of trust towards the healthcare system and those that work within this system. To date, only one research study has assessed the correlation between racial identity and medical mistrust (Shelton et al., 2010). Examining the nativity differences in racial identity and medical mistrust is essential to understanding the potential differences between these two groups since cultural differences may exist.

Racial pride has been identified as a factor that impacts trust, or lack thereof. Pride in one's race will vary from individual to individual even within the same racial group. Understanding the various levels of pride within those who self-identify as Black is essential and of cultural importance. The next section discusses the patient-physician relationship, specifically the importance of effective health related communication among those who have chronic illnesses. Further the effects that the patient-physician communication has on the development of trust will be explored.

**Patient-physician communication.** The patient and physicians relationship is essential and critical especially among vulnerable patients due to their high level of reliance on the physician's knowledge and skills (Goold & Lipkin, 1999). Although power is not a critical element in the patients-physician relationship, it often times is a factor, especially for vulnerable patients and if the physician is tyrannical (Goold & Lipkin, 1999). Trust is essential in the patient-physician relationship because it increases the chances of the patient disclosing pertinent health related information to the physician (Lazare, Putnam, & Lipkin, 1995). Lack of trust has been shown to decrease the number of health care visits associated with HIV treatment (Whetten et al., 2006).

The medical component of HIV seropositive individual is essential, and often, a large portion of their lives. Having a good patient-physician relationship among HIV seropositive individuals is associated with adherence to treatment regimen (Friedland & Williams, 1999). Although conversation about HIV may be difficult and embarrassing for both the physician and patient (Wilson, 1997), it is essential to ensure adherence to a medication regimen. Due to the growing number of antiretroviral medications and the importance of adherence to medications, communication or lack thereof between the physician and patient can either promote or prevent medication adherence (Wilson & Kaplan, 2000). Adherence to treatment recommendations is associated with better health outcomes (Wilson & Kaplan, 2000; Levinson, Lesser, & Epstein, 2010).

Within the HIV seropositive community, Blacks are less likely to receive antiretroviral treatment (Gebo et al., 2005), to adhere to treatment regimen (Bogart et al., 2010; Friedland & Williams, 1999; Zolnierrek & DiMatteo, 2009), and to obtain HIV viral suppression (Pence et al., 2008), regardless of socioeconomic status and access to HIV care (Saha et al., 2010). Schneider and colleagues (2004) conducted a study to examine which aspects of the physician and patient's relationship is linked with better adherence to antiretroviral medications. The results indicated that older patients, having good mental health, and believing that taking antiretroviral medication would increase the quality of HIV related care received had better adherence to medication. This study concluded that addressing the patient-physician relationship is beneficial when addressing medication adherence among HIV seropositive patients. Saha et al. (2010) indicate that these racial disparities could be due to the lack of trust that Blacks hold

towards physicians. Increasing interpersonal relationship between physicians and patients is essential to increase the exchange of health information and foster congruence in health care decisions (Zolnierrek & DiMatteo, 2009).

A meta-analysis conducted by Zolnierrek and DiMatteo (2009) found that physicians who communicated effectively using verbal or non-verbal communication, empathy, rapport, and mutual decision making with their patients had higher adherence to treatment recommendations compared to physicians who did not have effective communication. Specifically, effective patient-physician relationship has been contributed to verbal and non-verbal communication, open exchange of questions and information, exchange of emotions such as empathy and concern, and mutual decision-making (Bensing & Dronkers, 1992; Roter, Frankel, Hall, & Sluyter, 2006; Roter et al., 1997). Communication between the physician and a patient is vital to ensure that the patient understand the extent of their illness, risks associated with the illness, and benefits of treatment (Chewning & Sleath, 1996).

To understand the impact of trust on racial disparities among Blacks living with HIV, Saha et al. (2010) conducted a study which asked patients about their race/ethnicity, trust of physician, sexual orientation, age, and sex. The results of the study indicated that Blacks had lower levels of trust, were less likely to receive antiretroviral medication even when eligible, less likely to report completing adherence to antiretroviral medication over a three-day period, and to have viral suppression compared to Whites. This study concluded in stating that the patient and physician relationship is essential to the

development of interpersonal trust, especially with Black patients and may contribute to the reduction of racial disparities and increase health outcomes.

Trust is affected by both verbal and nonverbal behaviors of the physician (Cook et al., 2004). Patients suggested that the level of eye contact, body language, attentiveness, and feedback provided by a physician impact the level of trust that the patient had towards the physician (Cook et al.). Communication, specifically the ways in which HIV/AIDS is discussed between a physician and their patient, impacts the patient-physician relationship. Communication between physicians and patients in regards to HIV, involves conversation about sexual behaviors, at-risk behaviors such as injection drug use, and death (Wilson, 1997). Effective communication about HIV/AIDS is vital to overcome the barriers that hinder HIV treatment recommendations (Wilson & Kaplan, 2000). Previous studies have shown that being of a lower socioeconomic status and a minority was correlated with poorer communication between the physician and patient (Kaplan, Greenfield, Gandek, Rogers, & Ware, 1996). Particularly, Blacks received lower quality of communication when Black patients visit with White physicians (Johnson et al., 2004). Physicians were less likely to be patient centered when communicating with Black patients than with White patients (Johnson et al.).

Johnson, Roter, Powe, and Cooper (2004) conducted a study to investigate the correlation between communication during medical visit between patients and physicians. A total of 458 Black and White patients in the Washington D.C. metropolitan area participated in this study. Johnson et al. collected data by audiotaping the medical appointments and coding the medical encounters. The duration of visit, verbal authority

of physician, and patient centered focus of the session were used to measure patient-physician communication. The results of the study found that physicians were 23% more likely to dominate the dialogue between the physician and the patient and were 33% less likely to be patient centered with Black patients compared to White patients. This study concluded in stating that the physician's should be more patient-centered and awareness of his or her affect when working with Blacks is essential to addressing racial disparities.

Epstein et al. (1998) explain barriers to and facilitation of HIV risk communication between patient and physicians. The results conveyed that the physician did not gather enough information to identify HIV risk behaviors. Specifically, physician's emotions and discomfort with discussing HIV interfered with the physician ability to assess HIV risk. In addition, physicians did not effectively communicate with patients. This study concluded in stating that obtaining patient's perspective and effective communication skills should be used with physicians when assessing HIV risk.

Wilson and Kaplan (2000) examined the relationship between patients, physicians, the length and number of visits, and physician characteristics and its affects on general communication and HIV-specific communication. The results implied that being a female, longer length of time spent with the physician during each visit, and longer duration of the patient-physician relationship were associated with better communication. Further, longer visit length is associated with better general communication in males. Lastly, longer length of time spent with the physician during each visit and lower stages of HIV/AIDS were associated with better HIV-specific communication. This study concluded in stating that medical establishments and

insurance companies should be aware that short length of time spent during each visit, compromises effective communication between the physician and patient.

In conclusion, effective communication between the patient and physicians is crucial especially when working with those who have been historically oppressed, have high levels of mistrust, and rely heavily on the physician's knowledge and skills to understand one's ailment (Goold & Lipkin, 1999). It is essential to understand culture and the effects it has on the patient-physician relationship, specifically among native and foreign-born Blacks living with HIV/AIDS because "culture is learned, shared, transmitted intergenerationally, and reflected in a group's values, beliefs, norms, behaviors, communication, and family and social roles" and "can influence health priorities, decisions, beliefs, and behaviors" (Kreuter & Haughton, 2006, p. 795).

### **Limitations of Current Literature**

Many research studies have pinpointed medical mistrust as a barrier to Blacks utilizing services (Benkert, Peters, Tate, & Dinardo, 2008; Mosley, Freed, Bullard, & Goold, 2007; Saha, Jacobs, Moore, & Beach, 2010). Some research has gone so far as to state that mistrust for medical services can be traced back to the TSUS (Gamble, 1997) or to indicate that slavery and other medical mistreatments are the link to medical mistrust within the black community (Byrd & Clayton, 2002; Fett, 2002; Gamble, 1997). The transition of studying medical mistrust has moved from racial and ethnic differences in medical mistrust, medical mistrust amongst Blacks, to medical mistrust among Blacks diagnosed with HIV. However, no research has specifically identified the difference between foreign and native-born Blacks diagnosed with HIV/AIDS and the cultural

factors (racial pride, religiosity, and communication) that could potentially influence medical mistrust (Zaller, Fu, Nunn, & Beckwith, 2011). To date, only one study has examined racial identity/pride and medical mistrust among HIV seropositive Blacks (Shelton et al., 2010). Examining the nativity differences in racial identity and medical mistrust is essential to understand the potential differences between these two groups, and subsequent treatment and prevention efforts in working with these populations.

Furthermore, research that utilizes the terms “African American” or “Black” often do not define the meaning of these words. For example, the words “American” may insinuate those who are native in the United States. Failure to define nativity within the “African American” and “Black” community when conducting research can yield misleading results. For instance, there are many social and cultural aspects such as spirituality/religion, stigma, and mistrust towards medical establishments that may differ between native and foreign-born Blacks.

### **Problem Statement**

Research to understand HIV/AIDS in the Black community is of significant importance because this disease disproportionately affects Blacks. Specifically, countless research studies have found that there are health disparities associated with HIV/AIDS among the Black community. Medical mistrust continues to play a role in Blacks accessing, continuing, and receiving medical services, especially those related to HIV treatment and care. To date, this author has found no article that examines how foreign-born Blacks differ from native-born Blacks living with HIV/AIDS in their experiences of medical mistrust. Further, lack of knowledge regarding the potential differences can

result in the inappropriate use of terms such as “African American” when including foreign-born Blacks currently residing in the United States. When a disease disproportionately affects one racial group, it is imperative to understand factors that may contribute to the rate of infection within this group.

The results gathered from this study can be used to create culturally-specific and sensitive interventions and preventions for native and foreign-born Blacks living with HIV in the United States. Historically, foreign-born Blacks have been stigmatized and identified as the groups that have introduced HIV to the United States. Ironically, Blacks continue to have high levels of mistrust for the government and are disproportionately affected by the virus. In order to tackle the NHAS of addressing racial disparities, we must first understand HIV and medical mistrust among native and foreign-born Blacks.

### **Statement of Purpose**

The purpose of this study is to determine if cultural differences exist in medical mistrust among native and foreign-born Blacks living with HIV who are currently receiving treatment in the United States. The hope of this researcher is to strengthen the current literature on racial differences among Blacks and illuminate possible drawbacks of grouping foreign-born and native United States born Blacks into one singular racial group.

### **Research Questions**

This study aims to answer three questions. First, do foreign-born and native-born Blacks significantly differ on their level of medical mistrust, racial pride, religiosity, trust in physician and communication? HIV seropositive foreign-born Blacks are triple



stigmatized due to being born in a country outside of the United States, HIV seropositive, and Black. Blacks in general have higher levels of medical mistrust (Boulware et al., 2003; LaVeist et al., 2000), which has been hypothesized to be linked to historical maltreatment of Blacks. Socio-politically, foreign-born Blacks have been blamed for introducing HIV to the United States and may express higher level of medical mistrust than their native-born counterparts.

The second research question inquires whether there was a prediction in medical from racial pride, communication, religiosity, nativity, age, and sex. HIV seropositive Blacks with greater religiosity may be more inclined to mistrust healthcare systems and medical providers because of a greater reliance on their spirituality, faith, and religious practices. Further, individuals with higher levels of racial pride have been shown to have higher levels of mistrust. A better understanding of mistrust among native and foreign-born Blacks with HIV/AIDS is needed to identify patient and cultural factors that should be addressed to reduce mistrust among native and foreign-born Blacks.

The last research question inquires which variables (medical mistrust, racial pride, religiosity, communication, length of service, nativity, age, and sex) contribute to explaining trust in one's physician? Foreign-born individuals often have language barriers and may have a difficult time communicating their wants and needs to their physician. Further, research has shown that physicians often have a hard time communicating about HIV (Wilson, 1997). In addition, Black patients receive lower quality of communication compared to their White counterparts when at a physician's office (Johnson et al., 2004). Examining whether communication, medical mistrust, and

nativity can predict trust in the physician may be beneficial when working with this population.

## **CHAPTER THREE**

This chapter provides a detailed explanation of the methods and research design that were employed during this study. The general aim of this study was to examine cultural differences in medical mistrust among native (individuals born in the United States) and foreign-born (individuals born outside of the United States) Blacks living with HIV who were receiving HIV-related treatment between February and June of 2014 in the United States.

### **Preliminary Investigation**

Prior to initiating this dissertation research, a preliminary investigation was conducted to gather information on the racial self-identification of native and foreign-born Blacks. This information was obtained to ensure that the terms used within this study were inclusive and contained terms that both native and foreign-born participants used when describing themselves. Often times in research, the words “African American” and “Black” are used interchangeably and the ethnic, cultural, or within group differences of those who are classified and self-identify as “African American” and “Black” are often overlooked. Further, the term “American” suggests that participants are born in the United States when in fact they may have been born elsewhere. The one-item questionnaire obtained information on how each member identified racially. This questionnaire was disseminated among three church sites (a) a Sierra Leone Methodist

church, (b) a Liberian Evangelical Lutheran church, and (c) a Southern Baptist church. The question asked, “what is your racial identification?” There were three response options, (a) Black, (b) African American, and (c) African. Thirty-two questionnaires were completed. After reviewing the data, participants hand written responses such as “Black American” and “Sierra Leonean” in addition to selecting one of the three original choices. The data obtained from this preliminary investigation was used to include, “Black American”, “West Indian American” and other as an option in the sociodemographic portion of this dissertation questionnaire.

### **Research Design**

A quantitative cross-sectional design was utilized to examine the variation in medical mistrust, religiosity, racial pride, and communication among HIV seropositive native and foreign-born Blacks. Cross-sectional research involves collecting data at one point in time (Dimitrov, 2008), and thus data was collected between the months of February and June of 2014. The data was collected using a self-administered paper or online questionnaire which consisted of instruments designed to measure medical mistrust, religiosity, racial pride, and communication between the patient and physician as well as information pertaining to sociodemographics. Prior to the initiation of this research study, it was approved by the institutional review board at George Mason University (see Appendix A) and this researcher received approval from each instruments’ author to utilize their survey.

## **Participants**

A national sample of 247 HIV/AIDS seropositive Black men and women, who were at least 18 years of age, were solicited to participate in this study. The sample size within this study was determined by utilizing Cohen's power analysis which revealed that the number of participants needed for a large effect size was based on the number of predictors within the study (Cohen, 1988). According to Field (2009), Cohen's benchmark of .8 is a suggested large effect size when conducting research. As the effect size increases, power increases. Research with large power increases the probability that the analysis will reject the null hypothesis, which will avoid conducting a type II error (Field, 2009, p.223). That is, the analysis will show a statistically significant difference when in fact a difference does exist. Field suggests that a sample size of 80 will suffice for up to 20 predictors (p. 223). Therefore, this researcher sought as many participants as possible to exceed the recommended sample size of 80, even though this study only had eight predictors.

Participants who were at least 18 years of age were recruited at two local sites (e.g. Jupiter and Triton), online list servers, and social media (e.g. Facebook). The names of the sites were changed to protect the confidentiality of the participants. Participants who were currently receiving HIV/AIDS related services were used within this study because previous research assessing medical mistrust primarily used participants who were receiving regular medical services. These participants in previous research were identified since they had continuous exposure to the health care system and therefore had

their perceptions regarding medical services influenced by these experiences (LaVeist, Nickerson, & Bowie, 2000).

Participants were recruited using a nonprobability convenience sampling. Only those who met the eligibility criteria participated in this study. Eligibility criteria consisted of (a) self-identifying as Black, (b) being at least 18 years of age, (c) receiving services during February and June of 2014, and (d) diagnosed with either HIV or AIDS. The eligibility criteria were used to address the gap in research (e.g. aggregating native and foreign-born Blacks into one category) and to ensure that only those who were of age could consent at the time of the study. Native-born individuals consisted of Blacks who were born in the United States or were United States citizens at birth. Foreign-born individuals consisted of Blacks who were born in a country other than the United States and were not United States citizen at birth. Participants consented prior to completing the questionnaire.

## **Procedure**

Three strategies were employed to recruit participants and varied based on each recruitment site. Recruitment took place in three locations, (a) Jupiter, (b) the Triton, and (c) online. At each location, participants were provided a consent form and the 56-item questionnaire.

**Jupiter.** Jupiter is located in a major metropolitan area on the Eastern coast of the United States and is the largest provider of HIV/AIDS in its state. As individuals checked-in for their routine appointments at Jupiter, those who met the eligibility criteria were handed a flyer by the front desk secretary (see Appendix B). Front desk secretaries

were aware of the participant's demographic breakdown based on the self-report information gathered during the participant's initial intake with Jupiter. This researcher was located in the library of the facility. Those who were interested in completing the survey met the researcher in the library and were handed the questionnaire and a pen to complete this study. This researcher read each question to those who requested assistance completing the questionnaire. After completion, participants were instructed to place the completed form into the locked drop box. If participants did not agree, they were instructed to turn in the questionnaire form and drop it off at the locked drop box located in the library, which only this researcher had the key. Those who answered all questions of the questionnaire were handed a \$5 Walmart gift card.

**Triton.** Triton is located in a suburban area near a major metropolitan on the Eastern coast of the United States. Participants were contacted by a Triton intern who followed a script which introduced the study and inquired whether individuals were interested in participating in this study (see Appendix C). The script used in this study was a modified form of the script used during the initial Medical Mistrust Index reliability and validation study (LaVeist, Isaac, & Williams, 2009). The Triton intern received training from this researcher on how to respond to specific questions that participants may have had on the questionnaire. The intern contacted only those who met the eligibility criteria. The questionnaire was administered via phone. The intern read each question and responses to each participant who agreed to complete the questionnaire. Those who answered all questions of the questionnaire received a \$5 Walmart gift card via mail.

**Online.** Participants were recruited using an advertisement that was emailed to community HIV programs and University list server, placed on HIV/AIDS related Facebook pages, and posted on HIV/AIDS related Twitter pages (see Appendix D). Participants completed the questionnaire online using the SurveyMonkey software platform. The setting on SurveyMonkey required participants to complete all questions on each page prior to advancing to the next page. Participants were allowed to leave the questionnaire website and return at a later date and time in order to complete the survey. Participants who completed the questionnaire online did not receive a \$5 Walmart gift card due to the anonymous nature of the online questionnaire.

### **Materials and Variables**

This study employed a 56-item self-administered questionnaire to obtain data on medical mistrust, cultural factors to include racial pride, religiosity, communication, sociodemographic, HIV status, and medical experiences.

**Consent form.** Prior to proceeding to the first section of the self-administered questionnaire, participants were provided a paper or online consent form in which they checked the “yes, I agree” option to participate in this study (see Appendices E, F, and G). To ensure confidentiality, a signature was not required on the consent form. However, each paper consent form and questionnaire had a unique identifier (e.g. 100A) at the bottom right of each page. If participants agreed, they were instructed to proceed to the following sections of the questionnaire. For the online questionnaire, participants were asked to read and consent to participate in the online questionnaire prior to proceeding to the remaining sections of the questionnaire (see Appendix G).



**Medical mistrust.** Instruments measuring only trust have been shown to not fully capture the essence of mistrust since mistrust is more than just the absence of trust (Armstrong et al., 2006); it is the existence of negative feelings such as distress and doubt (Thompson et al., 2004). For this purpose, the first section of the questionnaire consisted of the *Medical Mistrust Index* (MMI) (LaVeist et al., 2000). Participants completed the MMI which consisted of 7-items. The MMI obtained information on participants' perceptions and degree of mistrust towards the health care system (see Appendix H). This assessment was used instead of other measures that address trust because it was applicable to those who were uninsured and those whose typical source of health care was not a primary care physician (LaVeist, Isaac, & Williams, 2009). It was expected that a majority of the participants who received services at Jupiter and Triton would be uninsured, and therefore the MMI was the most appropriate instrument to use.

In order to assess validity of the MMI, a sample of 1,784 cardiac hospital patients were utilized (LaVeist, Nickerson, & Bowie, 2000), with further analysis conducted on 327 participants in the community (LaVeist, Isaac, & Williams, 2009), which assessed the validity of the 17-item and a subsequent shorter 7-item questionnaire. The reliability coefficients (Cronbach's alpha) were .74 for the 17-item questionnaire and .76 for the 7-item questionnaire. The test-retest reliability was at moderately strong levels (0.70) and was significant at  $p < .01$  level. The MMI was significantly negatively correlated with other measures of trust such as the Trust in Physicians Scale ( $r = -.23, p < .01$ ) and the Generalized Trust Scale ( $r = -.15, p = .01$ ). Items on the MMI included, "healthcare organizations have sometimes done harmful experiments on their patients without their

knowledge” and “I trust that healthcare organizations will tell me if a mistake is made about my treatment.” Participants’ selections were based on a 4-point Likert-type scale which ranged from “strongly disagree”, “disagree”, “agree”, and “strongly agree.” To measure medical mistrust, the mean score was calculated within the scale. The Cronbach’s alpha for the Medical Mistrust Index for this study was .92, which suggested excellent levels of internal consistency.

This researcher added an additional question following the MMI which asked, “from whom have you heard about health care organizations deceiving or misleading African Americans/Black patients?” Participants were given the following options, family, friends, media (movies, television, news, and radio), church, personal experience, historical events, and other and were instructed to check all that applied. This question was added to gather information on the where participants were receiving information regarding mistreatment of Blacks within the medical system.

**Cultural components.** The racial pride and religiosity subscales were used to assess cultural factors (see Appendices H and I). Both assessments were subscales of the brief scales to measure cultural variables that are significant to the Black community. The *Brief Scales to Measure Collectivism, Religiosity, Racial Pride, and Time Orientation* were developed by Lukwago, Kreuter, Bucholtz, Holt, and Clark (2001). The original scale was developed to understand cultural variables in Black women, but each subscale has been used to examine cultural factors in Black men as well (Halbert et al., 2009). The religiosity and racial pride subscales have been shown to be linked with health related views and practices (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003).

The validation of this scale was conducted on a sample of 44 low-income Black women and found that this scale was related with health related knowledge and behavior (Lukwago et al., 2001) and was subsequently used on a larger sample of 321 Black women (Steele-Moses et al., 2009).

***Religiosity.*** The religiosity subscale consisted of nine items, which obtained information regarding participants' religious behaviors as well as their endorsement of religious values (see Appendix I). The religiosity subscale provided choices on a 4-point Likert-type scale which ranged from "strongly disagree" to "strongly agree." Questions varied from involvement in religious services, praying, and spirituality. Example questions consisted of "I talk openly about my faith with others" and "I have a personal relationship with God." This questionnaire took no more than five minutes to complete. From a sample of 41 Black women the Cronbach's alpha for the religiosity subscale was .88 (Lukwago et al., 2001) and .84 respectively (Steele-Moses, 2009) and the test-retest reliability was ( $r = .89; p < .01$ ) (Lukwago et al., 2001). In another study on 71 Black and 125 White males living with cancer, the internal consistency was at acceptable levels with a Cronbach's alpha of .94 (Halbert et al., 2009). Religiosity was measured by summing the scores within the subscale which ranged from 9-36. The Cronbach's alpha for the religiosity subscale within this study was .90, which revealed excellent internal consistency.

***Racial pride.*** The racial pride subscale examined participants pride towards the Black race (see Appendix J). In addition, this subscale examined the participant's attentiveness and participation in traditional practices and having optimistic racial

outlooks. The subscale consisted of seven items and provided choices on a 4-point Likert-type scale which ranged from “strongly disagree” to “strongly agree.” Example questions consisted of “the individuals I respect most in life are Black” and “racial pride is important for developing strong Black families.” The Cronbach’s alpha for the racial pride subscale was .84 (Lukwago et al., 2001) and .88 (Steele-Moses et al., 2009) respectively and the test-retest reliability was at moderate levels ( $r = .52$ ;  $p < .01$ ) (Lukwago et al., 2001). Higher scores on the racial pride subscale indicated higher levels of racial pride. To measure racial pride, the sum of the scores were calculated within the subscale and ranged from 9-36. The Cronbach’s alpha for the racial pride subscale for this study was .78, which suggested fair internal consistency.

**Communication.** Wilson and Kaplan (2000) developed the *Physician-Patient Communication Scale* (see Appendix K), comprised of nine items. The first five items comprised the general communication subscale and the later four consisted of the HIV-specific communication scale. The general communication scale was scored on a 5-point Likert scale with response choices of “poor”, “fair”, “good”, “very good”, and “excellent.” The HIV-specific communication scale was also scored on a 5-point Likert scale with an additional option of not applicable (N/A) added. An example question consisted of “how is the medical staff who takes care of your HIV at explaining the results of tests in a way that you understand.” The scale was developed using 264 HIV seropositive patients and 69 of their primary care physicians to determine the quality of the patient-physician communication. Two measures were established during this study: the general communication and the HIV-specific communication. The internal

consistency reliability was at adequate levels as shown by the Cronbach's alpha (.93) for the general communication scale and (.92) for the HIV-specific communication scale with a Pearson's correlation coefficient of .70 for the two subscales. The reliability of both subscales was not reported. Higher scores on the communication scale indicated greater levels of overall communication between the physician and the patient. To measure the patient-physician communication, the mean score was calculated within the scale. An average score of a five will indicate high levels of communication and an average score of a one will indicate low levels of communication. The Cronbach's alpha for the communication scale within this study was .93, which suggested great internal consistency.

**Coping.** Three questions were asked to obtain information about how participants coped with their HIV/AIDS diagnosis (see Appendix L). The first question asked, "how do you cope with your current diagnosis?" Participants were instructed to select all options that applied. Choices for response were, "I pray/go to church", "I see a counselor/psychologist", "I talk to my friends/family", "I use substance", "I am not coping", and "other". With the "other" response, participants were asked to specify how they cope. The second question asked, "how is your coping technique working for you?" Choices were based on a 10-point rating scale, with response choice 1 being "not working", 5 being "neither", and 10 being "working well". The third question was a two-part question that asked, "are you willing to see a counselor/psychologist regarding any health concerns?" Responses were either "no" or "yes". This question was measured at the nominal level. Immediately following was a one item follow-up question, which

asked, “if yes, would it make a difference if the counselor was African American/Black?” Responses to this question were “no” or “yes” and were measured at the bi-nominal level.

**Nativity.** Nativity was captured by a two-item question that asked, “Were you born in the United States?” Response consisted of “no” or “yes”. Further, participants were asked a follow-up question which requested participants to specify length of time living in the United States or place of birth if the response was “no.” If the response was “yes”, participants were asked to indicate length of time living in Virginia and state of birth. For those who completed the questionnaire online, the question asked participants to specify their state of residency, how long they resided in this state, and their state of birth. The length of time living in the United States was asked as a back-up question in the event the researcher is unable to collect data on enough foreign and native-born Blacks to compare. Nativity was recoded into a dichotomous variable. Those who indicated that they were born in the United States were assigned a value of “2” and those who reported that they were foreign-born were assigned a value of “1.”

The second question asked, “were your parents born in the United States?” Responses consisted of “no” or “yes”. Further, participants were asked a follow-up question which requested participants to specify length of time their parents have lived in the United States or place of birth if the response was “no.” If the response was “yes”, participants were asked to indicate the state in which their parents resided, length of time their parents resided within this state, and state of birth.

**Sociodemographic.** The self-administered demographic questionnaire consisted of 6-items (see Appendix L). The sociodemographic portion of the questionnaire

requested that participants report their racial identification, age, sex, sexual orientation, marital status, and education level. Response categories for education level ranged from 1 (“grades 1-6”) to 10 (“doctoral degree”).

**HIV/AIDS information.** The HIV/AIDS information was obtained to ensure that those who were diagnosed with HIV or AIDS were included in the study. Further, the HIV/AIDS information was gathered to disaggregated those who were HIV seropositive from those who were AIDS seropositive because HIV and AIDS have different diagnoses and definitions (CDC, 2011b; CDC, 2012c). The HIV status was obtained by five questions, with the first question asking, “what is your current diagnosis?” Responses to this question were either HIV or AIDS (see Appendix L). Participants were also asked to provide the number of years that he or she has known about his or her HIV and AIDS status. Although this data was collected in years, the data was transformed into months. The data was transformed into months to be consistent with the ways in which data was collected in previous research, as well as to capture those participants who were aware of their HIV/AIDS serostatus for less than one year. Further, many participants entered their responses in months instead of years, when completing the survey. The fourth question asked, “when did you seek help for your HIV/AIDS diagnosis?” Responses consisted of “immediately”, “within 6 months”, “within 1 year”, and “after 1 year”. In addition, a one-item question obtained disclosure of HIV/AIDS status. The specific question asked, “besides your medical staff, who knows about your HIV/AIDS status?” Participants were instructed to select all options that applied. Options consisted of, “no one”, “mother”, “father”, “sister”, “brother”, “other relatives”, “friends”, “pastor or church members”,

“employer”, and “other.” Participants were asked to specify who knew about their HIV/AIDS if the “other” option was chosen.

**Medical experiences.** Medical experiences were evaluated by the length of time the individual received services at the treatment site (Jupiter, Triton, or other) (see Appendix L). Specifically, participants were asked how long they received services at the treatment site for their HIV/AIDS care. The length of time was used as a control variable to determine the relationship towards services. Participants’ health insurance status was assessed by a single item question. Those who reported that they received Medicaid were assigned a value of “2”, Medicare assigned a value of “3”, private insurance assigned a value of “4”, uninsured was assigned a value of “1”, and other form of insurance were assigned a value of “0.” Further, participants were asked to what extent he or she trusts his or her physician. Responses consisted of “I do not trust my physician at all”, “I do not trust my physician”, “I neither trust nor distrust my physician”, “I trust my physician”, and “I trust my physician very much.” In addition, participants were asked whether they recently changed service providers with responses being “no” or “yes”.

**Race of providers/staff.** Previous research has shown that less than 3.5% of Black physicians in the United States treat people living with HIV/AIDS (American Medical Association, 2010). Further, research has shown that Black patients who have non-Black treating physicians report lower levels of satisfaction and involvement in services (Cooper-Patrick et al., 1999). Therefore, to capture whether this trend was similar within this studies participants’, the race of the treating physician and other staff were gathered. Race of providers and other staff was evaluated by three questions (see



Appendix L). Specifically, the questions asked about the race of the participants' physician/nurse practitioner, nurse/social worker, and other staff (secretary, pharmacist, etc.) respectively. Responses consisted of "no" or "yes".

### **Research Questions**

1. Do foreign-born and native-born Blacks significantly differ on their level of medical mistrust, racial pride, religiosity, trust in physician, and communication?
  - Null hypothesis ( $H_0$ ): there was not a statistically significant nativity difference in medical mistrust, racial pride, religiosity, communication, and trust for physician.
  - Alternative hypothesis ( $H_a$ ): there was a statistically significant nativity difference in medical mistrust, racial pride, religiosity, communication, and trust for physician.
2. Do racial pride, communication, religiosity, nativity, age, and sex predict medical mistrust from native and foreign-born Blacks living with HIV/AIDS?
  - Null hypothesis ( $H_0$ ): there was not a statistically significant prediction in medical mistrust from racial pride, communication, religiosity, nativity, age, and sex.
  - Alternative hypothesis ( $H_a$ ): there was a statistically significant prediction in medical mistrust from racial pride, communication, religiosity, nativity, age, and sex.

3. Do the following variables: communication, religiosity, racial pride, length of service, nativity (native or foreign-born), age, sex, and medical mistrust contribute to explaining trust in physician?

- Null hypothesis ( $H_0$ ): there was not a statistically significant prediction in trust in physician from communication, religiosity, racial pride, length of service, nativity, medical mistrust, age, and sex.
- Alternative hypothesis ( $H_a$ ): there was a statistically significant prediction in trust in physician from communication, religiosity, racial pride, length of service, nativity, age, sex, and medical mistrust.

### **Statistical Analysis**

The data from the paper questionnaire was manually entered into SurveyMonkey. This was done so that the extracted data from SurveyMonkey uploaded into excel would have the same codes. The data was extracted from SurveyMonkey into excel and then imported into the Statistical Package for the Social Sciences (SPSS) version 21.0 software. The data was scored and analyzed using SPSS. The following statistical analyses were used to address each research question (see Table 2). Univariate descriptive statistics were employed to describe participants in terms of sociodemographic, HIV/AIDS information, and coping, as well as to examine the frequency and skewness of the data.

Univariate data analyses were employed to address the first research question which aimed to determine whether nativity differences existed in medical mistrust, racial pride, religiosity, and communication. Specifically a one-factor Analysis of Variance

(ANOVA) was generated with nativity being the factor variable with two levels (foreign and native-born) and the dependent variables were medical mistrust, racial pride, religiosity, communication scale, HIV-specific communication subscale, and the general communication subscale. The ANOVA was utilized since it takes into consideration the intercorrelations among the dependent variables and reduced type I error (rejecting the null hypothesis when it was in fact true) (Dimitrov, 2008). There were three assumptions in ANOVA (Dimitrov, 2008, p.219). The assumptions are (a) observations are independent from one another, (b) normal distribution within each dependent variable, and (c) equal variances across each group (Dimitrov, 2008, p.234). If it was determined that there was a statistical significance, each individual scale (medical mistrust, religiosity, communication, and racial pride) was examined.

To address the second research question, multiple regression analyses were generated to determine the association between the dependent variable (medical mistrust) from the three independent variables (racial pride, religiosity, communication, nativity, age, and sex). Lastly, to test the third research question a multiple linear regression was conducted, however, a stepwise selection was utilized. Specifically, a stepwise selection was conducted to determine the unique contribution made to trust in physician by communication, religiosity, racial pride, length of service, nativity (native or foreign-born), age, sex, and medical mistrust (Dimitrov, 2008).

Table 2

*Data Analytic Technique*

Question	Data source	Data type	Analysis
1. Do foreign-born and native-born Blacks significantly differ on their level of medical mistrust, racial pride, religiosity, and communication?	1. Medical Mistrust Index 2. Racial Pride subscale 3. Religiosity subscale 4. Physician-Patient communication a. General b. HIV-specific  By Nativity	1. 4-point scale 2. 4-point scale 3. 4-point scale  4a. 5-point scale 4b. 6-point scale	ANOVA
2. Is there an association between medical mistrust and the following three variables respectively: racial pride, communication and religiosity?	1. Medical Mistrust Index 2. Racial Pride subscale 3. Religiosity subscale 4. Physician-Patient communication 5. Nativity 6. Age 7. Sex	1. 4-point scale 2. 4-point scale 3. 4-point scale 4. 6-point scale 5. Nominal scale 6. Ratio scale 7. Nominal scale	Multiple Regression (simultaneous entry)
3. Which variable (communication, religiosity, racial pride, length of service, nativity, and medical mistrust) contribute to explaining trust in physician?	1. Medical Mistrust Index 2. Racial Pride subscale 3. Religiosity subscale 4. Physician-Patient communication 5. Length of service 6. Nativity 7. Trust in Physician 8. Age 9. Sex	1. 4-point scale 2. 4-point scale 3. 4-point scale 4. 6-point scale 5. Ordinal scale 6. Nominal scale 7. 5-point scale 8. Ratio scale 9. Nominal scale	Multiple Regression (step-wise)

## CHAPTER FOUR

This chapter, by conducting univariate and multivariate analyses, explores the differences, specifically cultural differences that exist among native and foreign-born Blacks living with HIV/AIDS. A detailed explanation of the response rates, sociodemographic characteristics of the participants, scale analyses, and the results of the study are provided.

### **Response Rate**

Between the Jupiter and Triton sites, this researcher had access to roughly 794 individuals who met the eligibility criteria. However, only a total of 16 participants completed the paper questionnaire at Jupiter and 25 participants at Triton, which equates to roughly (5.16%) access to participants at both sites. Overall, a total of 256 HIV seropositive native and foreign-born Blacks participated in this study. Of those, 93.36% ( $n = 239$ ) participants completed the questionnaire in its entirety, and 7.64% ( $n = 17$ ) did not complete the questionnaire in its entirety. The majority of participants (83.40%) completed the online questionnaire, and the remainder of the study participants completed the paper questionnaire in person from Triton (10.12%) and Jupiter (6.48%) (see Table 3).

Table 3

*Collection Sites Questionnaire Completion Rate (n= 247)*

Site	<i>n</i>	%
Online	206	83.40%
Jupiter	16	6.48%
Triton	25	10.12%

*Note.* Valid percent, which calculates the statistics based on the number of respondents per item, were used. *n* includes participants who started the questionnaire but did not complete the survey in its entirety.

**Omitted data.** For the purpose of this dissertation, of the 17 surveys that were not completed in its entirety, four surveys were omitted from data analysis because participants selected “no” to the informed consent and therefore declined completing the questionnaire. An additional five surveys that were partially completed were omitted from data analysis because participants completed fewer than five questions of the 56-item questionnaire. The remaining eight surveys were included in the data analysis because participants completed at least half of the items on the questionnaire.

For the purposes of this study, only the scales where responses were provided for each item within the scale were used for analysis. This conditional inclusion was applied to the responses of only eight participants because the other participants responded to all items on each scale. That is, if participants failed to answer all items within a scale (e.g. medical mistrust, racial pride, religiosity, and communication), their responses for the scale were omitted from the analyses. Therefore in total 247 surveys were included in data analysis. Only the data from participants who fully answered questions on a scale were used in analysis. One option to addressing the missing data was to use mean

substitution. However, mean substitution has been found to neither increase nor decrease the overall mean, does not make significant changes to the regression coefficient, and is frowned upon in research as it does not allow the research to acknowledge the limitations of the data (Osborne, 2012, p.106). Osborne recommends that researchers do not use mean substitution, but instead are transparent and report all instances of missing data (2012, p.131).

**Analysis.** A one-way ANOVA was conducted to determine whether there was a statistically significant difference in the data collection methods (e.g. online versus paper). The ANOVA test was conducted to investigate whether participants who completed the paper questionnaire versus the online questionnaire significantly differed on medical mistrust, racial pride, religiosity, trust in one's physician, and communication. For the purpose of an ANOVA, the dependent variables; the Medical Mistrust Index, racial pride subscale, religiosity subscale, communication scale, and the two subscales of the communication scale, HIV-specific and general communication, and trust in physician, were examined. The fixed factor was the collection method (online/paper). All three assumptions for the ANOVA were held except for the assumption of equal variances across each dependent variable for the trust in physician, and the racial pride subscale. This means that the results yielded in this study were liberal which made it easier to reject the null hypothesis than it typically should be. The assumption of equal variances was held for the Medical Mistrust Index, religiosity subscale, communication scale, general communication subscale, and HIV-specific communication subscales (see Table 4).

Table 4

*Levene's Test of Equality of Error Variance for the Collection Method on Seven Dependent Variables*

Site	<i>F</i>	<i>df1</i>	<i>df2</i>	<i>p</i>
Medical Mistrust	.001	1	231	.97
Racial Pride	11.60	1	231	<.01
Religiosity	1.90	1	231	.17
Communication Scale	3.00	1	231	.08
General Communication	1.98	1	231	.16
HIV-specific Communication	1.98	1	231	.16
Trust in Physician	15.43	1	231	<.01

*Note.* *df* = degrees of freedom.

**Medical mistrust.** The Levene's test of equality of error variances showed that the assumption of homogeneity of variance was met for medical mistrust,  $F(1, 231) = .001$ ,  $p = .97$ . The ANOVA  $F$ -test results indicated that there was a statistically significant difference in medical mistrust among the two collection methods,  $F(1, 231) = 8.47$ ,  $p < .01$ ,  $p\eta^2 = 0.035$ , which implied that 3.5% of the variance in medical mistrust was accounted for by the two collected methods (see Table 5). The Cohen's recommendations for interpreting  $p\eta^2$  demonstrated that the effect size of .035 was relatively small (Cohen, 1988). The descriptive statistics revealed that individuals who completed the online questionnaire had higher levels of medical mistrust ( $M = 2.80$ ) compared to those who completed the paper questionnaire ( $M = 2.46$ ) (see Table 6).

**Racial Pride.** The Levene's test of equality of error variances indicated that the assumption of homogeneity of variance was not met for the racial pride subscale,  $F(1,$



231) = 11.60,  $p < .01$ . The ANOVA  $F$ -test results indicated that there was not a statistically significant difference in racial pride among the two collection methods,  $F(1, 231) = .33$ ,  $p = .57$  (see Table 5).

**Religiosity.** The Levene's test of equality of error variances indicated that the assumption of homogeneity of variance was met for the religiosity subscale,  $F(1, 231) = 1.90$ ,  $p = .17$ . The ANOVA  $F$ -test results indicated that there was a statistically significant difference in religiosity among the two collection methods,  $F(1, 231) = 8.50$ ,  $p < .01$ ,  $p\eta^2 = 0.035$ , which implied that 3.5% of the variance in religiosity was accounted for by the two collected methods (see Table 5). The Cohen's recommendations for interpreting  $p\eta^2$  demonstrated that the effect size of .035 was relatively small (Cohen, 1988). The descriptive statistics revealed that individuals who completed the online questionnaire had lower levels of religiosity ( $M = 3.06$ ) compared to those who completed the paper questionnaire ( $M = 3.30$ ) (see Table 6).

Table 5

*One-Way Analysis of Variance for the Collection Methods on Seven Dependent Variables*

Variable and Source	<i>SS</i>	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>	$p\eta^2$
Medical Mistrust						
Between	3.81	1	3.81	8.47	<.01	.035
Within	103.79	231	.45			
Racial Pride						
Between	.05	1	.05	.33	.57	.001
Within	36.73	231	.16			
Religiosity						
Between	1.99	1	1.99	8.50	<.01	.035
Within	54.18	231	.24			
Communication Scale						
Between	56.11	1	56.11	81.59	<.01	.261
Within	158.86	231	.69			
General Communication						
Between	1.24	1	1.24	1.43	<.01	.221
Within	205.16	231	.87			
HIV-specific Communication						
Between	88.98	1	88.98	83.86	<.01	.266
Within	245.08	231	1.06			
Trust in Your Physician						
Between	2.40	1	2.40	3.91	.05	.017
Within	141.60	231	.61			

*Note.* *SS* = sum of squares; *df* = degrees of freedom; *MS* = mean squares;  $p\eta^2$  = partial eta squared.

**Communication.** The Levene's test of equality of error variances indicated that the assumption of homogeneity of variance was met for the communication scale,  $F(1, 231) = 3.00, p = .08$ . The ANOVA  $F$ -test results indicated that there was a statistically

significant difference in religiosity among the two collection methods,  $F(1, 231) = 81.59$ ,  $p < .01$ ,  $p\eta^2 = 0.261$ , which implied that 26.1% of the variance in the communication scale was accounted for by the two collected methods (see Table 5). The Cohen's recommendations for interpreting  $p\eta^2$  demonstrated that the effect size of .261 was relatively large (Cohen, 1988). The descriptive statistics revealed that individuals who completed the online questionnaire reported lower levels of overall communication between themselves and their physician ( $M = 2.87$ ) compared to those who completed the paper questionnaire ( $M = 4.16$ ) (see Table 6).

**General communication.** The Levene's test of equality of error variances indicated that the assumption of homogeneity of variance was met for the general communication subscale,  $F(1, 231) = 1.98$ ,  $p = .16$ . The ANOVA  $F$ -test results indicated that there was a statistically significant difference in the general communication subscale among the two collection methods,  $F(1, 231) = 65.62$ ,  $p < .01$ ,  $p\eta^2 = 0.221$ , which implied that 22.1% of the variance in the general communication subscale was accounted for by the two collected methods (see Table 5). The Cohen's recommendations for interpreting  $p\eta^2$  demonstrated that the effect size of .221 was relatively large (Cohen, 1988). The descriptive statistics revealed that individuals who completed the online questionnaire reported lower levels of general communication between themselves and their physician ( $M = 3.16$ ) compared to those who completed the paper questionnaire ( $M = 4.31$ ) (see Table 6).

**HIV-specific communication.** The Levene's test of equality of error variances indicated that the assumption of homogeneity of variance was met for the HIV-specific

communication subscale,  $F(1, 231) = 1.98, p = .16$ . The ANOVA  $F$ -test results indicated that there was a statistically significant difference in the general communication subscale among the two collection methods,  $F(1, 231) = 83.86, p < .01, p\eta^2 = 0.266$ , which implied that 26.6% of the variance in the HIV-specific communication subscale was accounted for by the two collected methods (see Table 5). The Cohen's recommendations for interpreting  $p\eta^2$  demonstrated that the effect size of .266 was relatively large (Cohen, 1988). The descriptive statistics revealed that individuals who completed the online questionnaire reported lower levels of HIV-specific communication between themselves and their physician ( $M = 2.33$ ) compared to those who completed the paper questionnaire ( $M = 3.96$ ) (see Table 6).

***Trust in physician.*** The Levene's test of equality of error variances indicated that the assumption of homogeneity of variance was not met for the trust in physician scale,  $F(1, 231) = 15.43, p < .01$ . The ANOVA  $F$ -test results indicated that there was a statistically significant difference in the trust in physician scale among the two collection methods,  $F(1, 231) = 3.91, p < .05, p\eta^2 = 0.017$ , which implied that 1.7% of the variance in the HIV-specific communication subscale was accounted for by the two collected methods (see Table 5). The Cohen's recommendations for interpreting  $p\eta^2$  demonstrated that the effect size of .017 was relatively small (Cohen, 1988). The descriptive statistics revealed that individuals who completed the online questionnaire reported lower levels of trust within their physician ( $M = 3.95$ ) compared to those who completed the paper questionnaire ( $M = 4.22$ ) (see Table 6).

Table 6

*Mean and Standard Deviation for the Collection Method and Seven Dependent Variables*

Variable	<i>N</i>	<u>Online</u>		<i>n</i>	<u>Paper</u>	
		<i>M</i>	<i>SD</i>		<i>M</i>	<i>SD</i>
Medical Mistrust	192	2.80	0.67	41	2.46	0.66
Racial Pride	192	2.97	0.36	41	3.01	0.55
Religiosity	192	3.06	0.47	41	3.30	0.54
Communication Scale	192	2.87	0.80	41	4.16	0.94
General Communication	192	3.16	0.81	41	4.31	0.89
HIV-specific Communication	192	2.33	1.00	41	3.96	1.18
Trust in Your Physician	192	3.95	0.70	41	4.22	1.08

Although statistically significant differences existed between the paper questionnaire and the online questionnaire on five (e.g. medical mistrust, religiosity, trust in physician, communication scale, general communication subscale, and HIV-specific communication subscale) of the seven dependent variables, there were relatively fewer participants who completed the paper questionnaire ( $n = 41$ ) than the online questionnaire ( $n = 192$ ). Due to the large variation in the number of participants who completed the online and paper questionnaire, the differences were not noteworthy. Specifically, further examination of the partial eta squared only showed that three (communication scale, general communication subscale, and HIV-specific communication subscale) of the six statistically significant variables had large effect sizes per Cohen's (1988) calculations. This indicated that the three remaining variables (e.g. medical mistrust, religiosity, and trust in physician) that reached statistical significance had small effect sizes. This suggested that the proportion of the total variability for each variable between the two groups (online/paper) was not practically significant (Cohen, 1988). That is, even though

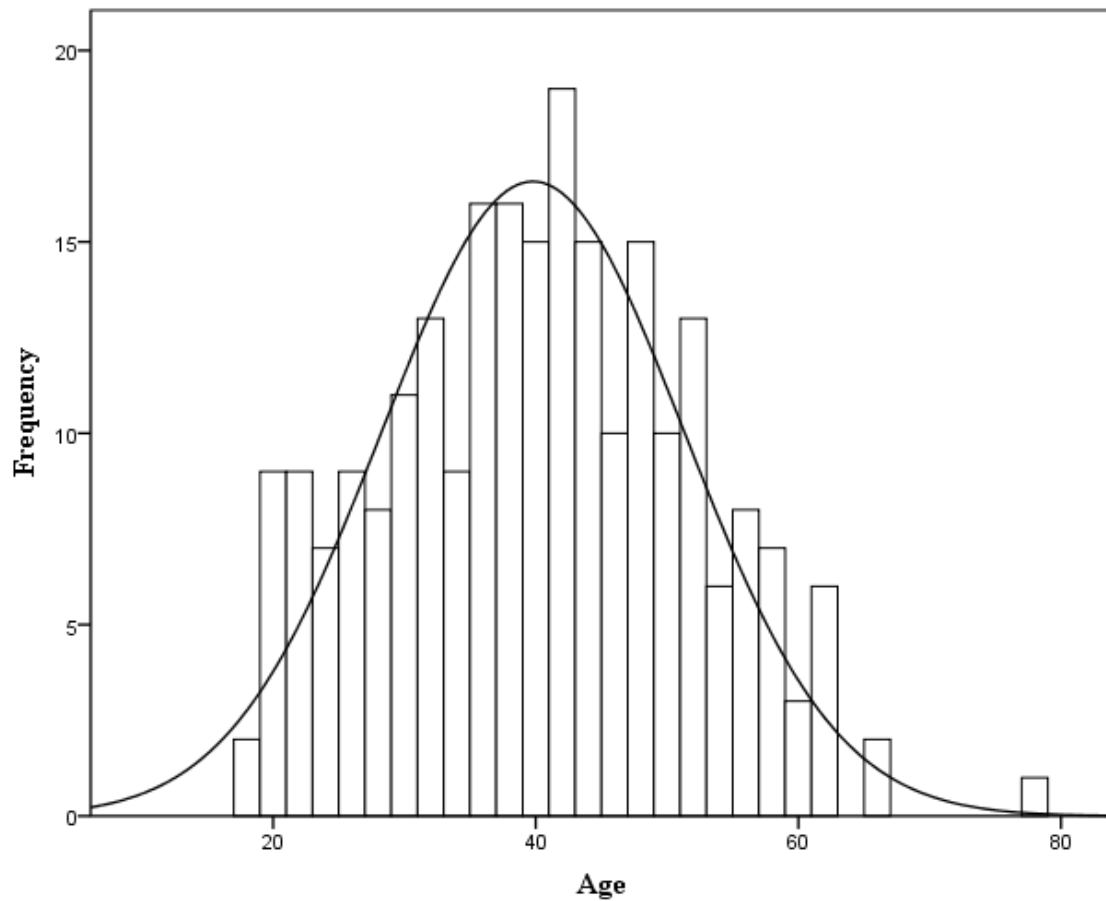
the variables reached statistical significance, the attributable and unique contribution of each variable (e.g. medical mistrust, religiosity, and trust in physician) individually to the differences between the paper and online group, was too small, and therefore no practical conclusions can be drawn from these results.

**Sample size.** Within this study, there were more online questionnaires completed compared to the paper version, and only the communication scale, general communication subscale, and HIV-specific communication subscale showed statistically significant differences and had large effect sizes. Although the difference amongst those who completed the online and paper questionnaire was statistical significance, it cannot show causation, meaning that the differences cannot be attributed to one group (e.g. paper questionnaire) receiving a \$5 incentive while the other group (e.g. online questionnaire) did not receive the incentive. The differences may be associated with each participant's communication background. That is, those who completed the paper questionnaire may have experienced better communication and perceived power associated with this communication since this researcher was present and reading the questionnaire. Further, this researcher was available to speak with participants, which may have increased the perception of improved communication since this researcher was collecting data at each treatment site. Although this researcher notified participants that this study was being conducted as part of a dissertation, participants may have affiliated the questions regarding participants' perceptions and services as a way for each site to improve upon their relationship with each participant. Lastly, participants who completed the paper

version of the questionnaire may have responded in a socially desirable manner due to the researcher being present.

### **Sociodemographics**

Univariate descriptive statistics were executed for each of the sociodemographic variables to determine the frequency and central tendencies of the data. The participants within this study were diversely represented with respect to age, with ages ranging from 18 to 77 ( $M = 39.78$ ,  $SD = 11.50$ ) (see Figure 1). A majority of the participants were between the ages of 28.23 and 51.23 years old. On average, female participants were younger  $M = 38.47$  ( $SD = 10.48$ ) than their male counterparts  $M = 40.73$ , ( $SD = 12.13$ ). Further, those who were foreign-born were typically younger  $M = 37.89$  ( $SD = 9.08$ ) in age compared to their native-born counterparts  $M = 40.66$  ( $SD = 12.40$ ).



*Figure 1.* Histogram of participants' age.

There were a total of 100 females and 139 males who completed the questionnaire (see Table 7). The majority of the participants were male (58.16%) with the remaining participants being female (41.84%). These results are lower than that reported by the CDC (2013d), which identified that in 2010 roughly 76% of all HIV seropositive adults and adolescents residing in the United States were males. Most participants reported their marital status as single (45.19%); however, several reported being in a relationship (23.01%), married (13.81%), divorced (13.81%), and widowed (4.18%). In terms of



sexual orientation, approximately half of the participants reported being heterosexual (50.21%). Finally, a majority of participants indicated having at least some college level education or higher (59.41%).

Table 7

*Demographic Characteristics of Participants (N = 247)*

Characteristics	<i>n</i>	%
Sex		
Male	139	58.16%
Female	100	41.84%
Sexual Orientation		
Heterosexual	120	50.21%
Gay/lesbian	75	31.38%
Bisexual	30	12.55%
Decline to answer	14	5.86%
Marital Status		
Single	108	45.19%
Married	33	13.81%
Divorced	33	13.81%
In a relationship	55	23.01%
Widowed	10	4.18%
Education		
Grades 1-6	0	0%
Grades 7-8	9	3.77%
Grades 9-12	45	18.83%
Some college	65	27.20%
College graduate	27	11.30%
Some graduate level	14	5.86%
High school graduate	43	17.99%
Some technical school	21	8.79%
Masters	13	5.44%
Doctorate	2	0.84%

*Note.* Valid percent, which calculates the statistics based on the number of respondents per item, were used.

Moreover, a majority of participants self-identified as Black (36.40%), with the remaining participants self-identifying as other (7.11%), African (10.46%), Black

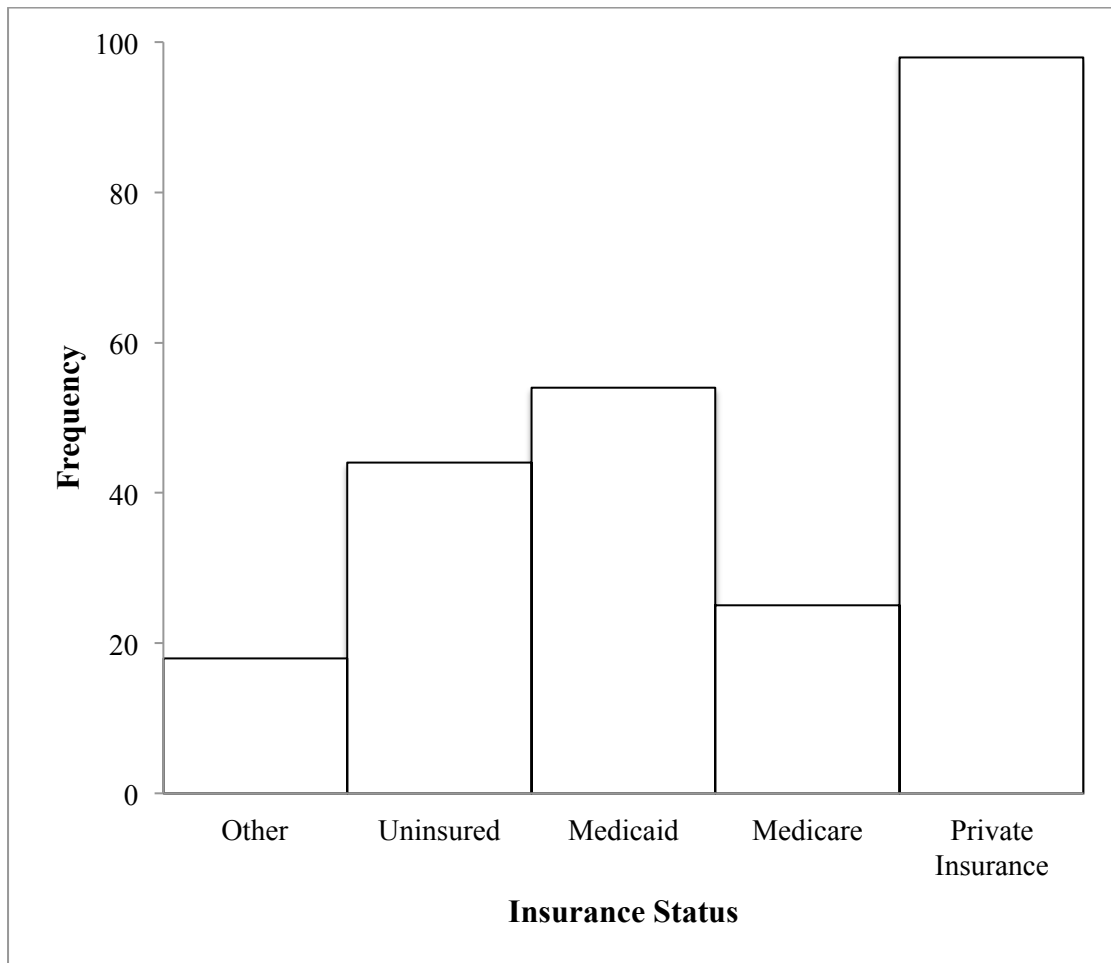
American (17.99%), African American (21.34%), and West Indian Black (6.69%) (see Table 8). A preponderance of participants (81.59%) had insurance during the time that the questionnaire was completed (see Figure 2). Approximately 83.83% of participants had not recently changed HIV/AIDS providers prior to completing the questionnaire. Further, more than half of the participants (68.20%) were born in the United States (see Table 8). Of the 31.80% who were born outside of the United States, 89.14% were born in a country located in Africa. Of the 235 participants who responded to the question, “what is your current diagnosis”, 85.96% indicated that they were HIV seropositive and 14.04% reported having an AIDS diagnosis. A majority of participants (42.13%) sought help from a professional immediately after receiving their HIV/AIDS diagnosis (see Table 8).

Table 8

*Sociodemographic Characteristics of Participants (N = 247)*

Characteristics	<i>n</i>	%
Self-Identification		
Other	17	7.11%
Black	87	36.40%
African	25	10.46%
Black American	43	17.99%
African American	51	21.34%
West Indian Black	16	6.69%
Insurance Status		
Other	18	7.53%
Uninsured	44	18.41%
Medicaid	54	22.59%
Medicare	25	10.46%
Private Insurance	98	41.00%
Born in the U.S.		
No	76	31.80%
Yes	163	68.20%
Provider Change		
No	197	83.83%
Yes	38	16.17%
Diagnosis		
HIV	202	85.96%
AIDS	33	14.04%
When Seek Help		
Immediately	99	42.13%
Within six months	61	25.96%
Within one year	24	10.21%
After one year	51	21.70%

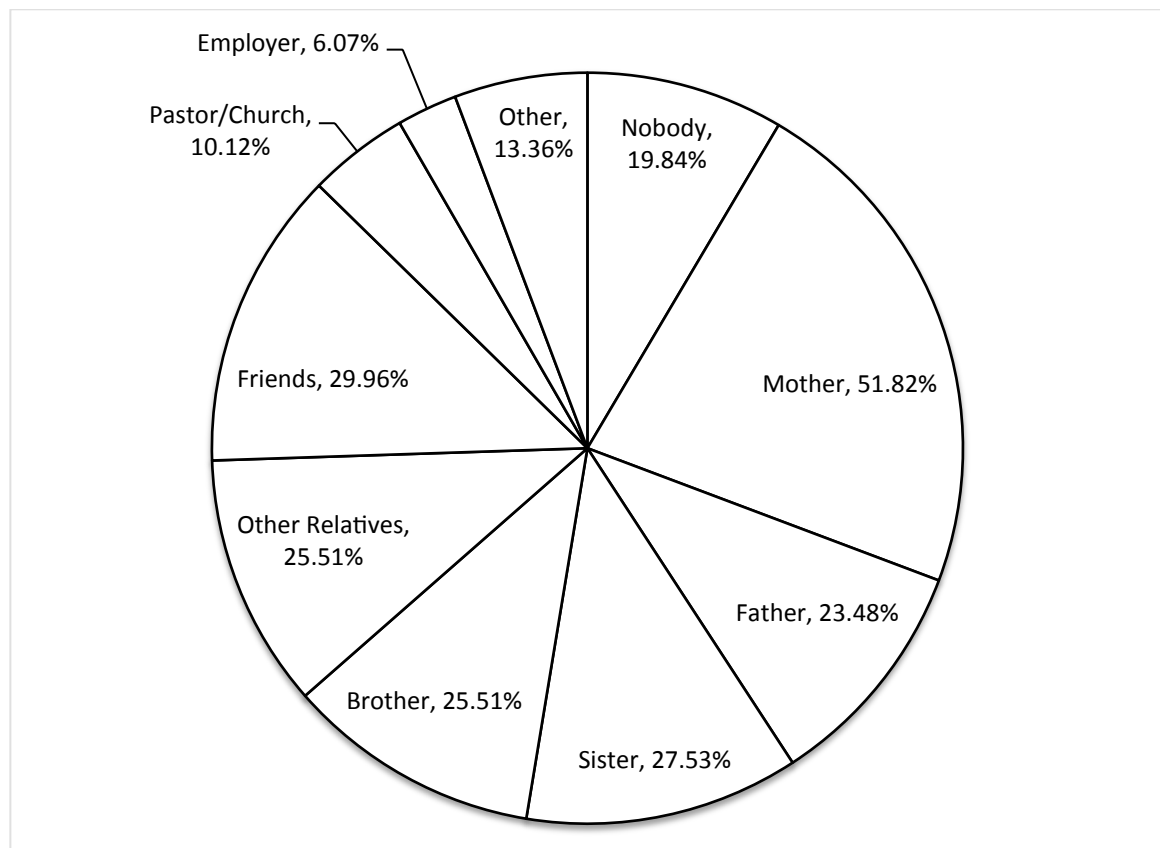
*Note.* Valid percent, which calculates the statistics based on the number of respondents per item, were used.



*Figure 2.* Histogram of participants' insurance statuses.

Of the participants who were HIV seropositive, the months known about HIV serostatus ranged from 10 to 360 ( $M = 103.58$ ,  $SD = 75.68$ ). This showed that on average, participants knew about their HIV status for 8 years and 6 months. Additionally, of the participants who had a diagnosis of AIDS, the months they had known about their AIDS diagnosis ranged from 12 to 372 ( $M = 123.27$ ,  $SD = 108.59$ ). This implied that on average, participants had known about their AIDS diagnosis for roughly 10 years and 3

months. When asked who knew about participant's serostatus, participants selected that their mother (51.82%), friends (29.96%), and sister (27.53%) knew about their serostatus more than any other person (see Figure 3). Fewer participants indicated that their employer (6.07%) were aware of their serostatus.



*Figure 3.* Pie chart of persons with knowledge of participants' HIV/AIDS status. The sum of the percentages will not total to 100% because participants were given the option to select all that apply.

As stated above, roughly 68.20% of all participants were native-born and 31.80% were foreign-born. More than half, 65.96% ( $n = 155$ ) of all participants who answered the

question, “were your parents born in the United States”, conveyed that their parents were native-born. The remaining 34.04% ( $n = 80$ ) had parents who were foreign-born. A crosstabulation was conducted to determine how many participants who were native-born also had parents who were foreign-born (see Table 9). The results showed that out of 160 participants who were native-born, 3.75% ( $n = 6$ ) had parents who were foreign-born. Moreover, out of 75 participants who were foreign-born, 1.33% ( $n = 1$ ) had parents who were native-born. Participants who were foreign-born reported living in the United States for 2 to 50 years ( $M = 24.28$ ,  $SD = 9.43$ ). In addition, 10.93% ( $n = 27$ ) of those who were native-born were born in Virginia, followed by 6.48% ( $n = 16$ ) in Washington D.C., and 4.05% ( $n = 10$ ) in New York. Roughly 2.43% ( $n = 6$ ) of those who were foreign-born were born in Nigeria, followed by 2.02% ( $n = 5$ ) who were born in Swaziland, Trinidad, and Ghana, respectively.

Table 9

*Crosstabulation of Participants and Parents Nativity Status*

		Parents born in the U.S.?		Total
		No	Yes	
Born in the U.S.?	Count	74	1	75
	No % within Born in the U.S.?	98.67%	1.33%	100%
	% Within Parent born in the U.S.?	92.50%	0.65%	31.91%
	% of Total	31.49%	0.43%	31.91%
	Count	6	154	160
	Yes % within Born in the U.S.?	3.75%	96.25%	100%
	% Within Parent born in the U.S.?	7.50%	99.35%	68.09%
	% of Total	2.55%	65.53%	68.09%
	Count	80	155	235
Total	% within Born in the U.S.?	34.04%	66.0%	100%
	% Within Parent born in the U.S.?	100%	100%	100%
	% of Total	34.04%	66.96%	100%

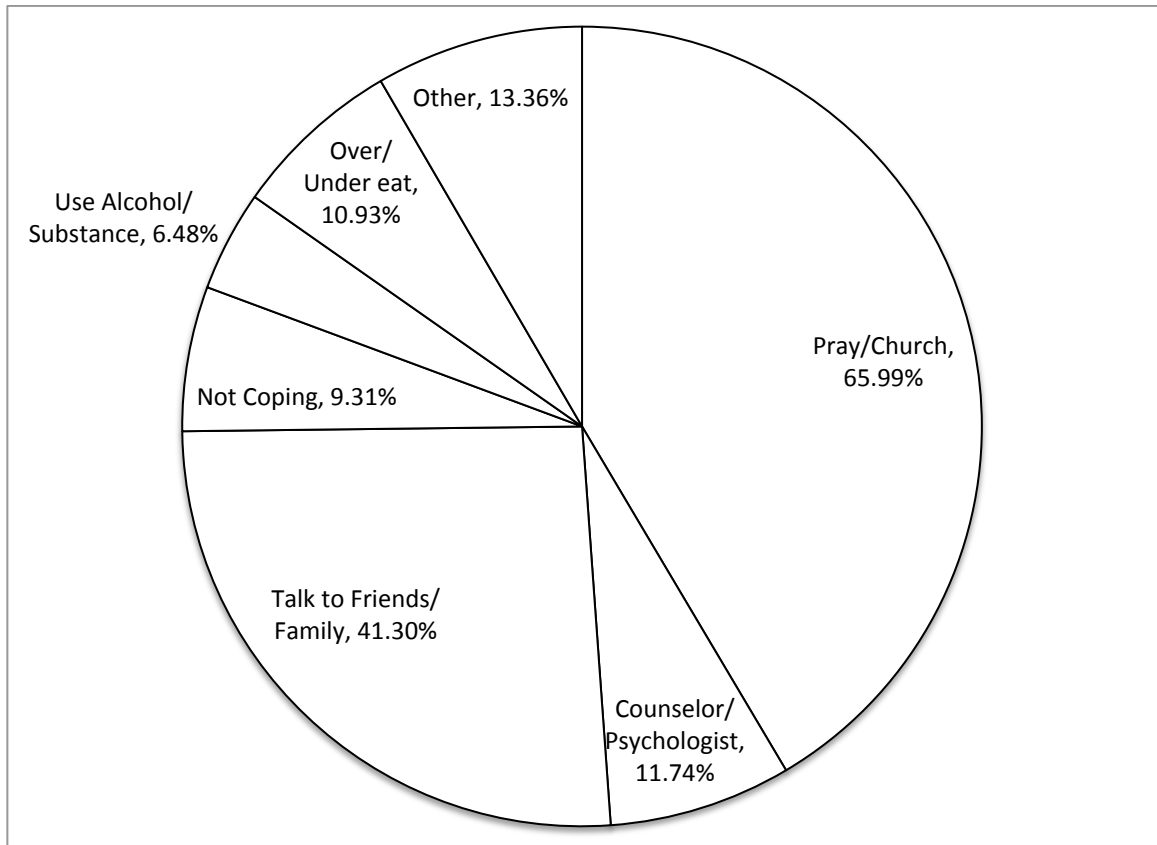
*Note.* Valid percent, which calculates the statistics based on the number of respondents per item, were used.

**Behaviors and Experiences**

**Coping.** Participants in this study endorsed praying or going to church as their most common coping strategies to deal with their HIV/AIDS diagnosis (see Figure 4). Approximately 41% of participants implied that they talked to their family and/or friends regarding their HIV/AIDS diagnosis, followed by 13.36% who selected other, 11.74% met with a psychologist or a counselor, 10.93% either over or under ate, 9.31% were not coping, and 6.48% used alcohol and/or an illegal substance to cope with their HIV/AIDS diagnosis. Lastly, 58.30% ( $n = 137$ ) of the participants were not willing to meet with a counselor or psychologist regarding their HIV/AIDS health concerns. Of the 41.70% ( $n = 98$ ) of participants who specified that they were willing to meet with a counselor or



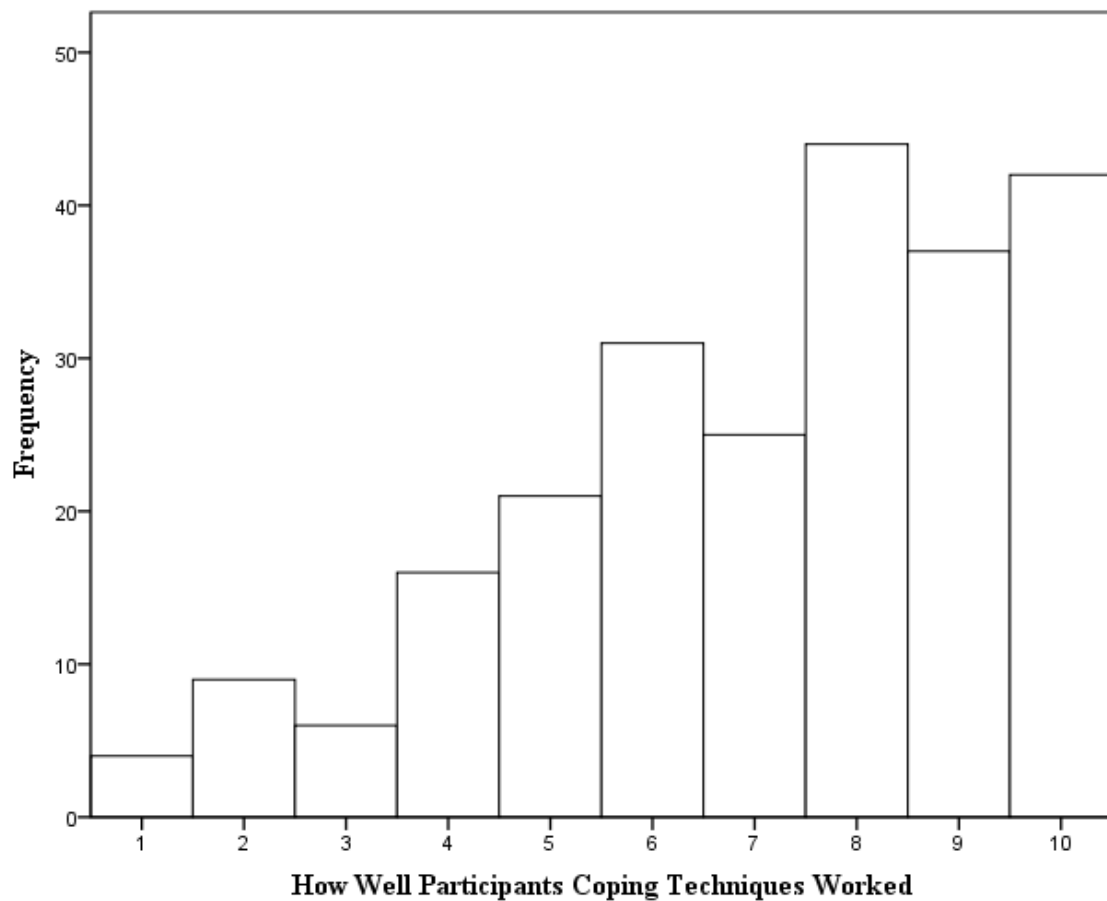
psychologist, 73.47% ( $n = 72$ ) denoted that it would not make a difference if the counselor/psychologist were Black. Only 26.53% ( $n = 26$ ) indicated that it would make a difference if the counselor/psychologist were Black.



*Figure 4.* Pie chart of coping mechanisms. The sum of the percentages will not total to 100% because participants were given the option to select all that apply.

Further, univariate descriptive statistics were executed for the coping variable to determine the frequency and central tendencies of the data. Of the 235 participants who responded to the question, “how is your coping technique working for you,” on a scale from 1 to 10; 1 represented not working, 5 indicated somewhat working, and 10 indicated

working well; a majority (62.98%) replied by selecting a 7 or higher which reflected that their coping technique was working adequately (see Figure 5). Only 1.70% of participants indicated that their coping technique was not working. An examination of the data shows that data from the coping variable was negatively skewed, which suggests that many of the participants' coping techniques were between the choices of somewhat working to working well.



*Figure 5.* Histogram of how well the coping mechanisms were working per participants' perception.

**Medical experience.** The medical experiences of participants were examined by analyzing the frequency of the length of services, race of providers at treatment facility, and the level of trust that participants had towards their treating physicians. Participants' length of services ranged from less than one month to 372 months ( $M = 85.74$ ,  $SD = 75.44$ ). This revealed that participants on average received services from their treating physicians for roughly 7 years and 2 months. In addition, a vast majority of participants indicated that their physicians or nurse practitioners (85.11%), nurses or social workers (79.15%), and other staff members (63.40%) at the treating facility were not Black. Finally, 54.47% ( $n = 128$ ) participants specified that they trust their physicians, followed by 25.11% ( $n = 59$ ) of participants who trust their physicians very much, 16.60% ( $n = 39$ ) neither trust nor mistrust their physicians, 2.98% ( $n = 7$ ) do not trust their physicians, and 0.85% ( $n = 2$ ) of participants who do not trust their physicians at all.

### **Scale Analyses**

Statistical analyses were conducted to examine the scales that assessed medical mistrust, racial pride, religiosity, and patient-physician communication; referred to as communication scale for the remainder of this document. The mean scores and standard deviation for the two subscales, general communication and HIV-specific, of the communication scale were also assessed. The mean score and standard deviations for all of the listed variables were examined. In addition, Cronbach's alpha coefficients were calculated for all of the listed variables. Research has shown that an alpha coefficient of .80 or greater indicates that the instruments has good internal consistency (Pedhazur & Schmelkin, 1991).

Scores on the scale measuring medical mistrust ranged from 1 to 4. Higher scores on the Medical Mistrust Index reflected higher levels of mistrust towards the medical system. For the entire sample, the mean score for this scale was 2.75 ( $SD = 0.67$ ) which suggested that typically, participants were moderately mistrustful of the medical system. The Cronbach's alpha for the Medical Mistrust Index was .92, which suggested excellent levels of internal consistency for this sample. The Medical Mistrust Index was non-normally distributed, with a skewness of  $-.48$  ( $SE = 0.16$ ) and kurtosis of  $0.04$  ( $SE = 0.31$ ) (see Figure 6) (Lomax & Hahs-Vaughn, 2012). The distribution of the scores were slightly negatively skewed with a normal kurtosis. This indicated that participants' scores on the Medical Mistrust Index were on the higher end of the distribution with fewer scores on the lower end of Medical Mistrust Index.

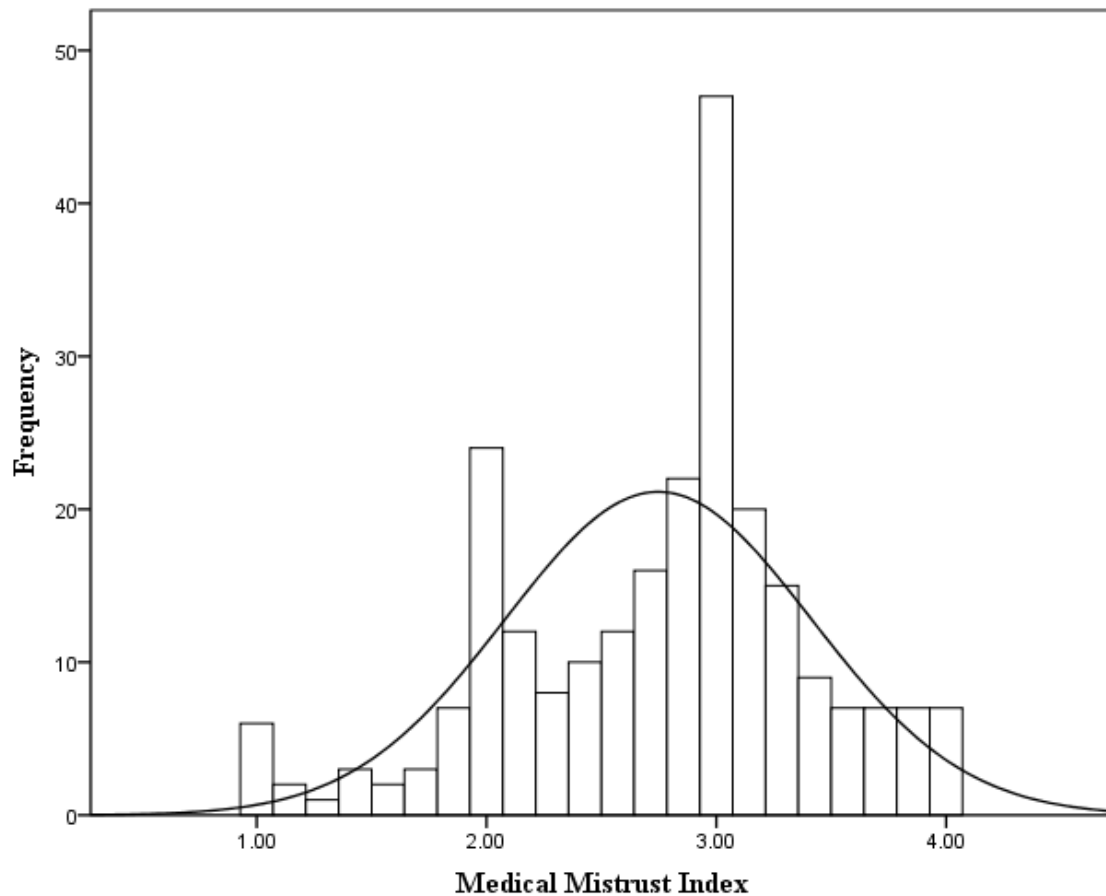


Figure 6. Histogram of participants' scores on the Medical Mistrust Index.

Scores on the subscales measuring racial pride ranged from 1 to 4. Higher scores on the racial pride subscale implied higher levels of pride in one's race. The mean score on the racial pride subscale was 2.99 ( $SD = 0.39$ ). This revealed that on average, participants had moderate levels of pride within their race. The Cronbach's alpha for the racial pride subscale was .78, which suggested fair internal consistency. Although the internal consistency estimates for the racial pride subscale was not at the 0.80 threshold, the alpha coefficient was similar to other estimates found in previous research (Lukwago

et al., 2003; Steele-Moses et al., 2009) suggested that .78 was an adequate finding for this study. The racial pride subscale was non-normally distributed, with a skewness of .10 ( $SE = 0.16$ ) and kurtosis of 1.60 ( $SE = 0.31$ ) (see Figure 7). The distribution of the scores showed that the skewness of the scores were within normal limits, with most scores falling on or around the mean (Lomax & Hahs-Vaughn, 2012). However, the distribution of scores also showed a positive kurtosis. Specifically, the kurtosis was leptokurtic with extremely high peaks.

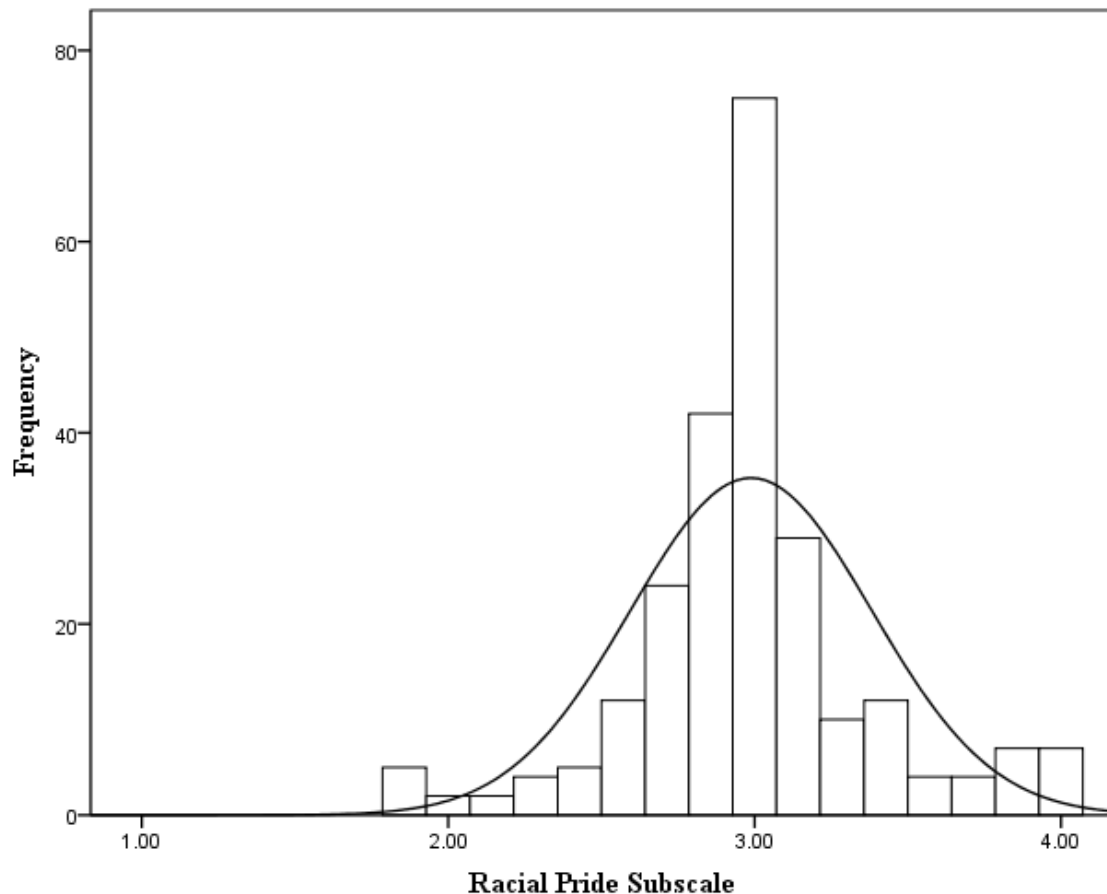


Figure 7. Histogram of participants' scores on the racial pride subscale.

Scores on the subscales measuring religiosity ranged from 1 to 4. The mean score on the religiosity subscale was 3.10 ( $SD = 0.48$ ), which showed that on average participants had high levels of religious activity, devotion, and spiritual views. The Cronbach's alpha for the religiosity subscale was .90, which revealed excellent internal consistency. The religiosity subscale was non-normally distributed, with a negative skewness of  $-.57$  ( $SE = 0.16$ ) and kurtosis of  $1.11$  ( $SE = 0.31$ ) (see Figure 8). The distribution of scores were slightly negatively skewed with a positive kurtosis. The kurtosis was also leptokurtic with extremely high peaks (Lomax & Hahs-Vaughn, 2012). This indicated that a majority of the scores were towards the higher end of the distribution.

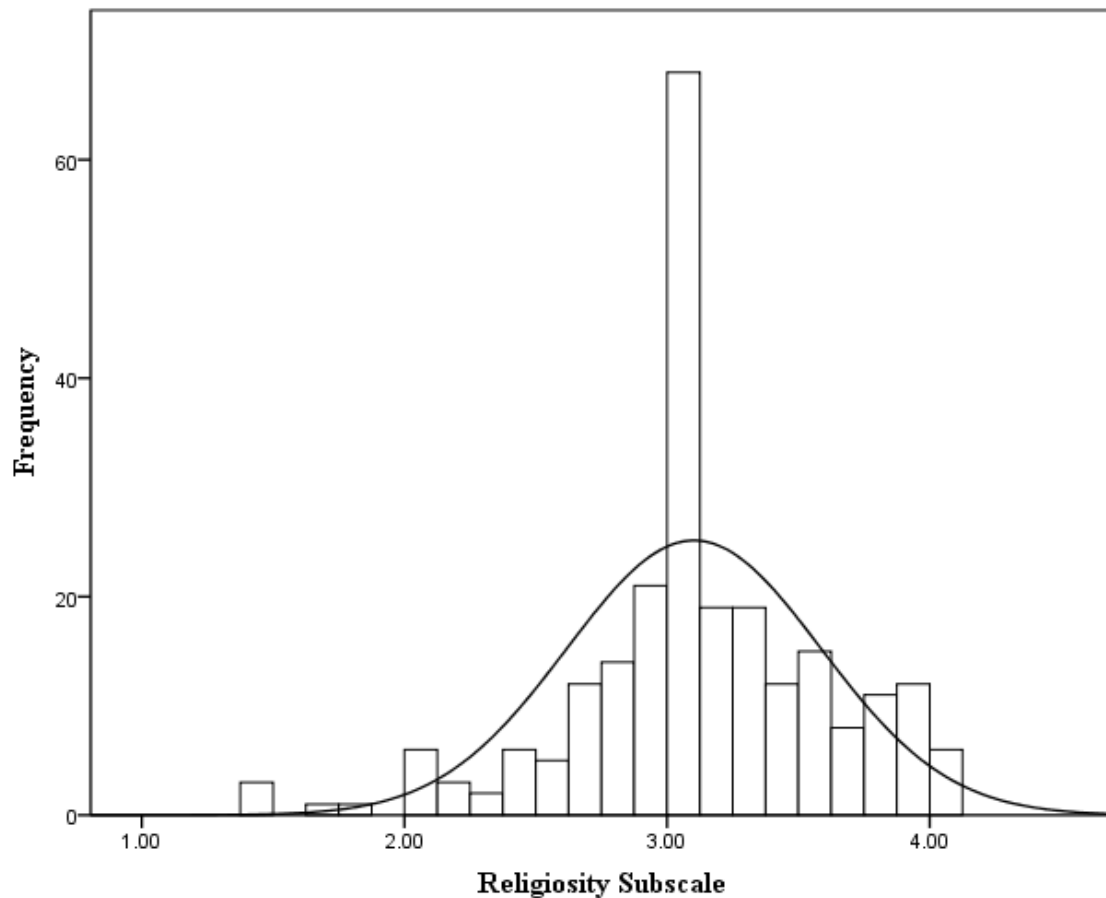


Figure 8. Histogram of participants' scores on the religiosity subscale.

Lastly, the overall scale mean for communication scale, which incorporates the HIV-specific and the general communication subscales was 3.07 ( $SD = 0.96$ ), which indicated that on average participants reported having “good” communication between themselves and their physicians. The Cronbach’s alpha for the communication scale was .93, which suggested great internal consistency. The communication scale was non-normally distributed, with a positive skewness of .41 ( $SE = 0.16$ ) and kurtosis of -0.14 ( $SE = 0.31$ ) (see Figure 9). The distribution of data were negatively skewed, however, the



kurtosis was within normal limits (Lomax & Hahs-Vaughn, 2012). This indicated that participants' scores typically were on the lower end of the communication scale with fewer scores on the higher end of the communication scale.

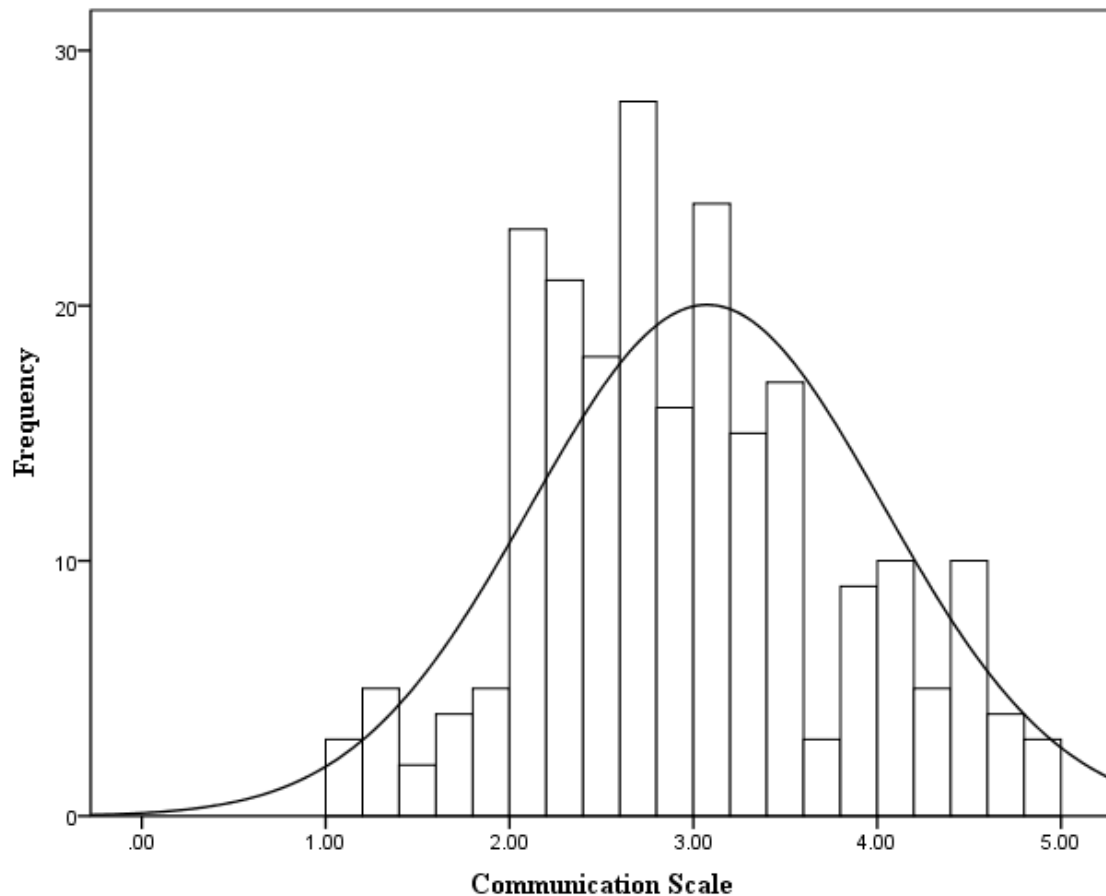


Figure 9. Histogram of participants' scores on the communication scale.

Two subscales (general and HIV specific) of the communication were assessed. The mean score on the general communication subscale was 3.34 ( $SD = 0.93$ ). This revealed that on average, participants reported having “good” general communication

between themselves and their physicians. The general communication subscale addressed areas such as presentation of health results, risk factors, and compassion. The Cronbach's alpha for the general communication subscale was .93, which revealed excellent levels of internal consistency. The general communication subscale was normally distributed, with a skewness of .15 ( $SE = 0.16$ ) and kurtosis of -0.35 ( $SE = 0.31$ ) (see Figure 10). The results of the skewness and kurtosis were within normal limits (Lomax & Hahs-Vaughn, 2012). The Pearson's correlation coefficient for the two subscales of the communication scale were calculated,  $r = .78$ ,  $p = .01$ .

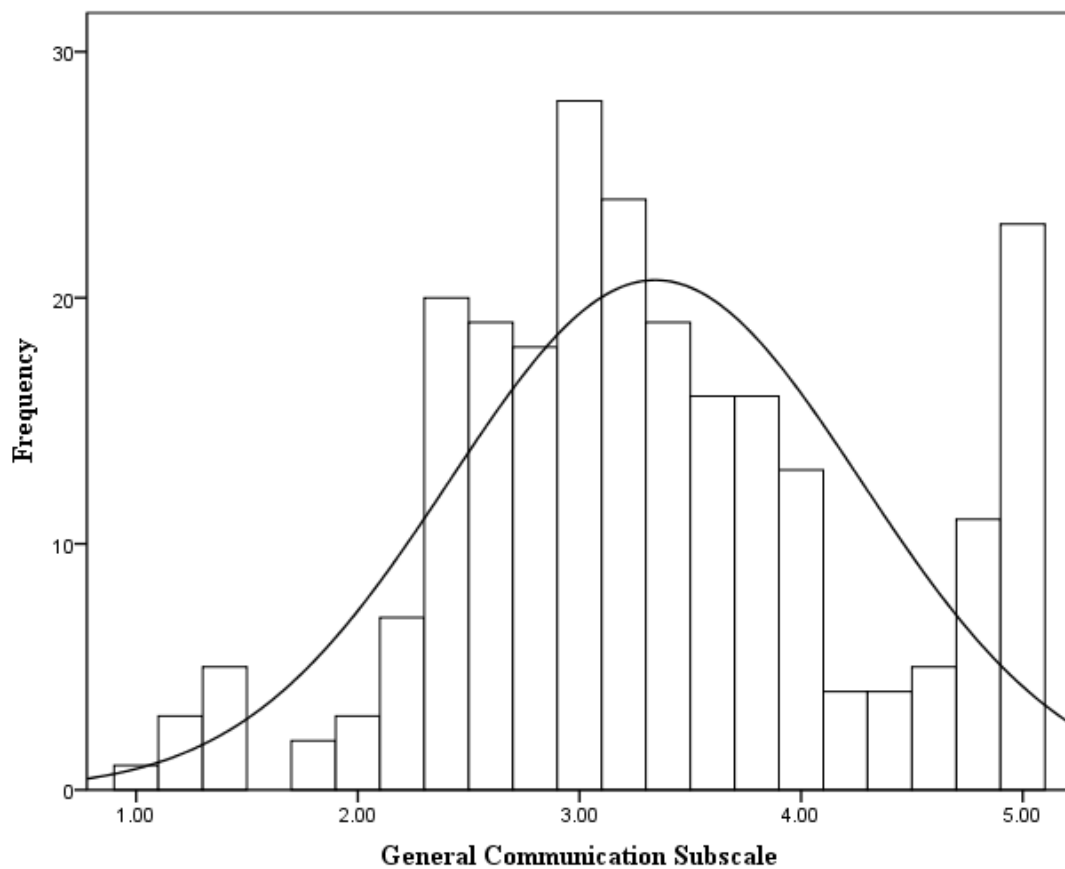
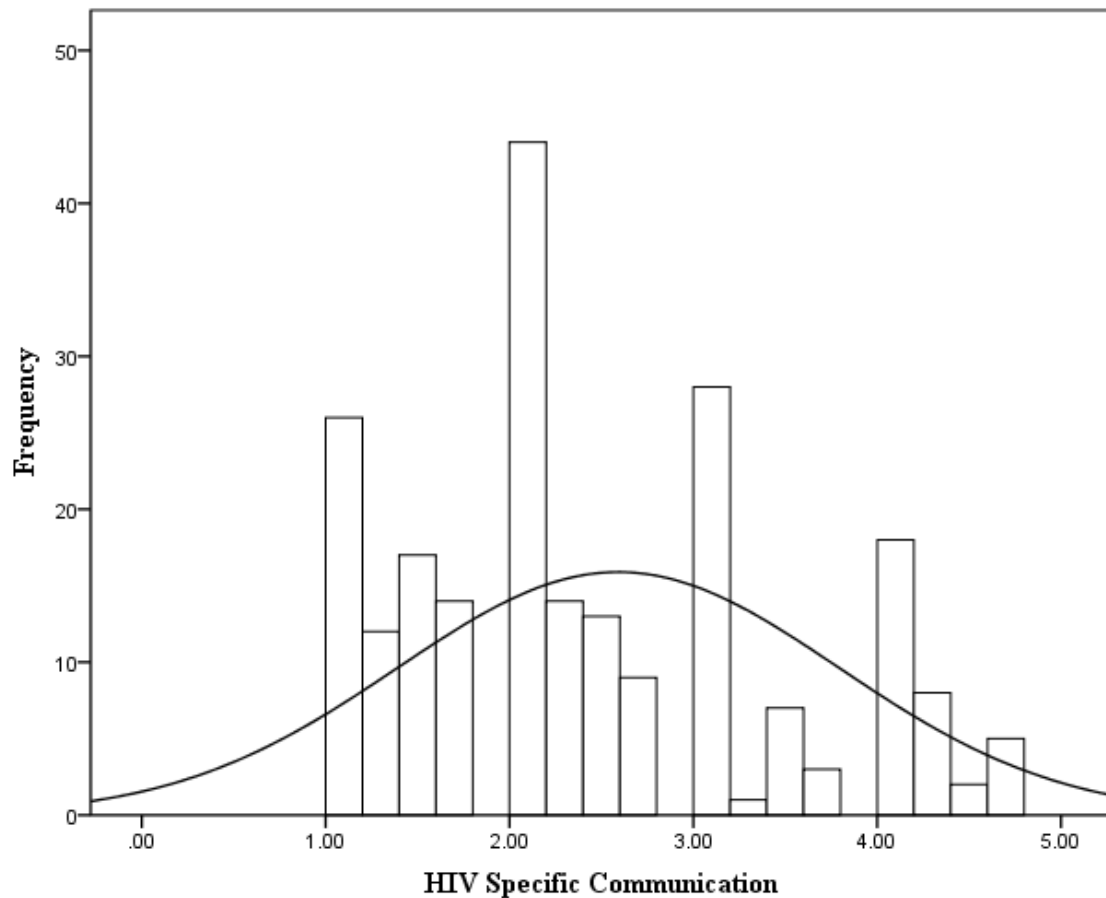


Figure 10. Histogram of participants' scores on the general communication subscale.

The mean score on the HIV-specific communication subscale was 2.59 ( $SD = 1.20$ ), which suggested that, on average, participants indicated that their HIV-specific communication between themselves and their physicians was “fair”. The HIV-specific communication subscale addressed areas such as sex and alcohol/drug use. The Cronbach’s alpha for the HIV-specific communication subscale was .86. The HIV-specific communication subscale was non-normally distributed, with a skewness of .59 ( $SE = 0.16$ ) and kurtosis of -0.70 ( $SE = 0.31$ ) (see Figure 11). The distribution of scores showed that the data were positively skewed with a negative kurtosis. Furthermore, the kurtosis was platykurtic, which implied a flattened distribution (Lomax & Hahs-Vaughn, 2012). This indicated that participants’ scores typically were on the lower end of the HIV-specific communication subscale with fewer scores on the higher end of the subscale.



*Figure 11.* Histogram of participants' scores on the HIV-specific communication subscale.

## Research Findings

**Research question #1.** “Do foreign-born and native-born Blacks significantly differ on their level of medical mistrust, racial pride, religiosity, trust in physician, and communication?”

An ANOVA test was conducted to investigate whether foreign-born and native-born Blacks differed significantly on their level of medical mistrust, racial pride, religiosity, trust in one’s physician, and communication. For the purpose of an ANOVA,

the dependent variables; the Medical Mistrust Index, racial pride subscale, religiosity subscale, communication scale, and the two subscales of the communication scale, HIV-specific and general communication, and trust in physician were examined. The fixed factor was born in the United States (no/yes). In order to have reliable results when utilizing an ANOVA, three assumptions must be met. For the purposes of this study, the three assumptions were (a) observations were independent from one another, (b) normal distribution within each dependent variable, and (c) equal variances across each group (Dimitrov, 2008, p.234). All three assumptions for the ANOVA were held except for the assumption of equal variances across each dependent variable for the Medical Mistrust Index, communication scale, trust in physician, general communication, and HIV-specific communication subscales. The assumption of equal variances was held for the racial pride and religiosity subscale. As indicated in the sociodemographic description, there were more native-born than foreign-born participants in this study which impacted the equal variance assumption. Specifically, as the sample size for the native-born participants increased, the smaller the variance was within this sample (Dimitrov, 2008, p.234). Therefore, since there were 163 native-born participants and only 76 foreign-born participants, the variances for the native-born and foreign-born participants were not equal.

***Medical mistrust.*** The Levene's test of equality of error variances showed that the assumption of homogeneity of variance was not met for medical mistrust,  $F(1, 237) = 6.74, p = .01$ . The ANOVA  $F$ -test results indicated that there was a statistically significant difference in medical mistrust among the foreign-born and native-born groups,

$F(1, 237) = 7.35, p < .01, p\eta^2 = 0.030$ , which implied that 3.0% of the variance in medical mistrust was accounted for by the two born in the United States groups (see Table 10). The Cohen's recommendations for interpreting  $p\eta^2$  demonstrated that the effect size of .030 was relatively small (Cohen, 1988). The descriptive statistics revealed that foreign-born individuals had lower levels of medical mistrust ( $M = 2.58$ ) compared to their native-born counterparts ( $M = 2.83$ ) (see Table 11).

**Racial Pride.** The Levene's test of equality of error variances indicated that the assumption of homogeneity of variance was met for racial pride,  $F(1, 237) = 3.74, p = .05$ . The ANOVA  $F$ -test results indicated that there was not a statistically significant difference in racial pride among the foreign-born and native-born groups,  $F(1, 237) = 3.31, p = .07$  (see Table 10).

**Religiosity.** The Levene's test of equality of error variances showed that the assumption of homogeneity of variance was met for religiosity,  $F(1, 237) = 0.29, p = .59$ . The ANOVA  $F$ -test results exposed that there was not a statistically significant difference in religiosity among the foreign-born and native-born groups,  $F(1, 237) = .00, p = .99$  (see Table 10).

**Communication.** The Levene's test of equality of error variances displayed that the assumption of homogeneity of variance was not met for communication,  $F(1, 237) = 30.94, p < .01$ . The ANOVA  $F$ -test results indicated that there was not a statistically significant difference in the communication scale among the foreign-born and native-born groups,  $F(1, 237) = 3.00, p = .07$  (see Table 10).

**General communication.** The Levene's test of equality of error variances indicated that the assumption of homogeneity of variance was not met for the general communication subscale,  $F(1, 237) = 30.14, p < .01$ . The ANOVA  $F$ -test results indicated that there was not a statistically significant difference in the general communication subscale among the foreign-born and native-born groups,  $F(1, 237) = 1.43, p = .23$  (see Table 10).

Table 10

*One-Way Analysis of Variance for Nativity Status on Seven Dependent Variables*

Variable and Source	<i>SS</i>	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>	$p\eta^2$
Medical Mistrust						
Between	3.25	1	3.25	7.35	.01	.030
Within	104.74	237	.44			
Racial Pride						
Between	.51	1	.51	3.31	.07	.014
Within	36.68	237	.16			
Religiosity						
Between	.00	1	.00	.00	.99	.000
Within	56.36	237	.92			
Communication Scale						
Between	3.00	1	3.00	3.27	.07	.014
Within	217.65	237	.92			
General Communication						
Between	1.24	1	1.24	1.43	.23	.006
Within	205.16	237	.87			
HIV-specific Communication						
Between	10.35	1	10.35	7.38	.01	.030
Within	329.62	235	1.40			
Trust in Your Physician						
Between	.71	1	.71	1.15	.29	.005
Within	143.30	233	.62			

*Note.* *SS* = sum of squares; *df* = degrees of freedom; *MS* = mean squares;  $p\eta^2$  = partial eta squared.

***HIV-specific communication.*** The Levene's test of equality of error variances indicated that the assumption of homogeneity of variance was not met,  $F(1, 235) = 31.83, p < .01$ . The ANOVA *F*-test results suggested that there was a statistically



significant difference in HIV-specific communication among the two nativity groups,  $F(1, 235) = 7.38, p = .01, p\eta^2 = 0.030$ , which indicated that 3.0% of the variance in HIV-specific communication was accounted for by the foreign-born and native-born (see Table 10). The Cohen's recommendations for interpreting  $p\eta^2$  illustrated that the effect size of .030 was relatively small (Cohen, 1988). The descriptive statistics exemplified that foreign-born individuals have lower levels of HIV-specific communication between themselves and their physicians ( $M = 2.30$ ) compared to their native-born counterparts ( $M = 2.74$ ) (see Table 11).

***Trust in physician.*** The Levene's test of equality of error variances revealed that the assumption of homogeneity of variance was not met for the trust in physician scale,  $F(1, 233) = 9.09, p < .01$ . The ANOVA  $F$ -test results indicated that there was not a statistically significant difference in the level of trust within one's physician among the two (foreign-born and native-born) nativity groups,  $F(1, 233) = 1.15, p = .29$  (see Table 10).

Table 11

*Mean and Standard Deviation for Born in the United States and Seven Dependent Variables*

Variable	<i>n</i>	<i>M</i>	<u>No</u>		<i>SE</i>	<i>n</i>	<u>Yes</u>		<i>SE</i>
			<i>SD</i>				<i>M</i>	<i>SD</i>	
Medical Mistrust	76	2.58	0.76	0.09		163	2.83	0.62	0.05
Racial Pride	76	2.92	0.31	0.04		163	3.02	0.43	0.03
Religiosity	76	3.10	0.46	0.05		163	3.10	0.59	0.04
Communication Scale	76	2.91	0.63	0.07		163	3.15	1.08	0.08
General Communication	76	3.24	0.62	0.07		163	3.40	1.04	0.08
HIV-specific Communication	76	2.30	0.83	0.09		161	2.74	1.32	0.10
Trust in Your Physician	75	4.08	0.59	0.07		160	3.96	0.86	0.07

*Note.* *SE* = standard error.

Due to the homogeneity of variance assumption being unmet in the medical mistrust and the HIV-specific communication ANOVA, nonparametric confirmatory examination was conducted using the Kruskal-Wallis test. The Kruskal-Wallis test is a nonparametric equivalent to the one-way ANOVA and can be used to address the violation of the homogeneity of variance assumption (Field, 2009, p. 559). The Kruskal-Wallis test was utilized since it simply ranks the data without taking into consideration the groups in which the data belong. The sum of the ranked data were then calculated and placed back into each designated group (Field, 2009, p. 560). The Kruskal-Wallis test illustrated that there were statistically significant nativity differences in medical mistrust,  $H(1) = 6.96, p = .01$ . The HIV-specific communication, although coming very close, failed to attain statistical significance  $H(1) = 3.393, p = .07$  (see Table 12).

Table 12

*Kruskal-Wallis Confirmatory Test for Seven Variables Examining Nativity Differences*

Variable	<i>M</i> <i>Rank</i>	<i>n</i>	$\chi^2(1)$	<i>p</i>
Medical Mistrust		239	6.94	.01
Foreign-born	102.80			
Native-born	128.02			
Racial Pride		239	1.60	.21
Foreign-born	111.88			
Native-born	123.79			
Religiosity		239	0.07	.79
Foreign-born	118.30			
Native-born	120.79			
Communication Scale		239	1.08	.30
Foreign-born	113.20			
Native-born	123.17			
General Communication		239	0.50	.48
Foreign-born	115.41			
Native-born	122.14			
HIV-specific Communication		237	3.39	.07
Foreign-born	107.13			
Native-born	124.61			
Trust in Your Physician		235	0.46	<.05
Foreign-born	121.99			
Native-born	116.13			

Note. Degrees of freedom in parenthesis.

**Research question #2.** “Do racial pride, communication, religiosity, nativity, age, and sex predict medical mistrust from native and foreign-born Blacks living with HIV/AIDS?”

The omnibus *F*-test indicated that the prediction of medical mistrust from all six predictors (racial pride, religiosity, communication, nativity, age, and sex) was

statistically significant,  $F(6, 232) = 10.86, p < .01$ . Furthermore,  $R^2 = .22$  indicated that 22% of the variance in the Medical Mistrust Index was accounted for by the variance in all six predictors. The regression equation in this case was  $\widehat{\text{medical mistrust}} = 0.282 (\text{racial pride subscale}) + 0.164 (\text{religiosity subscale}) + (-0.264) (\text{communication scale}) + 0.283 (\text{born in the United States}) + (-0.001) (\text{age}) + (-0.033) (\text{sex}) + 1.770$ . For a 1-unit increase in the communication scale, controlling for all other predictors, the Medical Mistrust Index decreased by 0.264 units. Further, for a 1-unit increase in racial pride subscale, controlling for all other predictors, the Medical Mistrust Index decreased by 0.282. For a 1-unit change in born in the United States, from foreign-born to native-born, controlling for all other predictors, the Medical Mistrust Index increases by 0.283 units. Lastly, for a 1-unit change in sex, from male to female, controlling for all other predictors, the Medical Mistrust Index decreases by -0.033 units. There was a statistically significant unique contribution for the racial pride subscale ( $p = .01$ ), the communication scale ( $p < .01$ ), and born in the United States ( $p < .01$ ), but not for the religiosity subscale ( $p = .06$ ), age ( $p = .87$ ), or sex ( $p = .68$ ).

Further, stepwise entry of all six predictors was conducted on the regression analysis to confirm the initial block entry. The results showed that the  $R^2_{\text{restricted}} = .21$  which indicated that 21% of the variance in Medical Mistrust Index was explained by the variance in three predictors (racial pride, communication scale, and born in the United States) (see Table 13). Given the relative consistency of religiosity across participants (native-born/foreign-born), it was removed in the stepwise analysis. Including religiosity, sex, and age into the regression equation model showed a non-significant difference. The

$R^2_{\text{change}}$  test indicated that there was a statistically significant difference in  $R^2$  for the full and restricted models. Therefore, the restrictive model was desired,  $F(3, 235) = 20.44, p < .01$  (Dimitrov, 2008). The regression equation in this case was  $\widehat{\text{medical mistrust}} = 0.349 (\text{racial pride subscale}) + (-0.253) (\text{communication scale}) + 0.277 (\text{born in the United States}) + 2.017$ . For a 1-unit increase in racial pride subscale, controlling for all other predictors, the Medical Mistrust Index increased by 0.349. Additionally, for a 1-unit increase in the communication scale, controlling for all other predictors, the Medical Mistrust Index decreased by 0.253 units. Lastly, for a 1-unit change in born in the United States, controlling for all other predictors, the Medical Mistrust Index increased by 0.277 units. There was a statistically significant unique contribution for the racial pride subscale ( $p = .01$ ), the communication scale ( $p < .01$ ), and born in the United States ( $p = .01$ ).

The examination of the standardized coefficient Beta ( $\beta$ ), portrayed that the most significant of all of the predictors was the communication scale ( $\beta = -.36$ ), followed by the racial pride subscale ( $\beta = .21$ ), and born in the United States ( $\beta = .19$ ) (see Table 13). Also, the squared partial correlation for the communication scale,  $(-0.359)^2 = 0.129$ , indicated that the unique contribution of the communication scale to the prediction of the Medical Mistrust Index was 12.9%. The squared partial correlation for the racial pride subscale,  $(0.203)^2 = 0.041$ , suggested that the unique contribution of the racial pride subscale to the prediction of medical mistrust was 4.1%. Lastly, the squared partial correlation for born in the United States,  $(0.189)^2 = 0.036$ , suggested that the unique contribution of born in the United States to the prediction of medical mistrust was 3.6%. However, because none of the predictors have a variance inflation factor (VIF) score

greater than ten, this disclosed that multicollinearity was not of concern in this case (Dimitrov, 2008, p. 195). Specifically, this indicated that each variable (communication scale, racial pride subscale, and born in the United States) are orthogonal to one another.

Table 13

*Summary of Multiple Regression Predicting Medical Mistrust (n =239)*

	Variable	B	SE B	$\beta$	$R^2$
Step 1	Racial pride subscale	0.35	0.10	.21**	.21**
	Communication scale	-0.25	0.04	-.36**	
	Born in the U.S.	0.28	0.09	.19**	
Step 2	Racial pride subscale	0.28	0.11	.17*	.22
	Communication scale	-0.26	0.04	-.38**	
	Religiosity subscale	0.16	0.09	.12	
	Born in the U.S.	0.28	0.09	.20**	
	Age	-0.00	0.00	-.01	
	Sex	-0.03	0.08	-.02	

*Note.*  $R^2_{\text{change}} = .207$  for Step 1.

\*  $\rho < .05$ . \*\*  $\rho < .01$ .

**Research question #3.** “Do the following variables: communication, religiosity, racial pride, length of service, nativity (native or foreign-born), age, sex, and medical mistrust contribute to explaining trust in physician?”

Multivariate correlational analyses were conducted to assess the linear relationships between trust in one’s physician and communication scale, Medical Mistrust Index, religiosity subscale, racial pride subscale, born in the United States (no/yes), length of services, age, and sex. The descriptive statistics of the multiple regression analyses are provided (see Table 14).

Table 14

*Descriptive Statistics of Multiple Regression for the Prediction of Trust in Physician (n = 235)*

Variable	<i>M</i>	<i>SD</i>
Trust in Physician	4.00	0.79
Communication Scale	3.09	0.97
Medical Mistrust	2.74	0.68
Religiosity	3.10	0.49
Racial Pride	2.98	0.40
Born in the U.S.	1.68	0.47
Length of Service	7.15	6.29
Age	40.00	11.46
Sex	0.42	0.50

The data were entered using a stepwise data-entry method. The stepwise data-entry method uses a process of constructing a model by continuously adding or eliminating each variable based on their predictive power (Dimitrov, 2008, p.209). The following variables were excluded from the model based on the stepwise data-entry; religiosity subscale, racial pride subscale, born in the United States, age, sex, and length of services. The results from the omnibus *F*-test indicated that the prediction of trust in physician from the one predictor in the restricted model (communication scale) accounted for a statistically significant amount of the variance in the prediction of trust in physician,  $F(1, 233) = 50.78, p < .01$ . Further,  $R^2 = .18$ , signified that 18% of the variance in trust in physician is accounted for by the variance in the communication scale. However, the change in  $R^2$  from the restricted model to full model was also statistically significant,  $R^2_{\text{change}} = .02, F(1, 232) = 4.48, p = .04$  (see Table 15). The  $R^2$  change test depicted that there was a statistically significant difference in  $R^2$  values for the full and restricted

models. Therefore, the more parsimonious full model was preferred,  $F(2, 232) = 28.01$ ,  $p < .01$  (Dimitrov, 2008, p.193). Lastly, the religiosity subscale, racial pride subscale, length of service, nativity, age, and sex did not account for a statistically significant proportion of the variance in trust in physician over and above the proportion accounted for by the communication scale and the Medical Mistrust Index and therefore were not included in the restricted or full model.

Table 15

*Summary of Multiple Regression Predicting Trust in Physician (n =235)*

	Variable	<i>B</i>	SE <i>B</i>	$\beta$	$R^2$
Step 1	Communication scale	0.34	0.05	.42**	.18**
Step 2	Communication scale	0.31	0.05	.38**	.19*
	Medical Mistrust Index	-0.15	0.07	-.13*	

*Note.*  $R^2_{\text{change}} = .016$  for Step 2 ( $p < .05$ ).

\*  $p < .05$ . \*\*  $p < .01$ .

The regression equation in this case was  $\widehat{\text{trust in physician}} = 0.306$  (*communication scale*) + (-0.154) (*Medical Mistrust Index*) + 3.475. For a 1-unit increase in the communication scale, controlling for all other predictors, the trust in physician, increased by 0.306 units. Further, for a 1-unit increase in the Medical Mistrust Index, controlling for all other predictors, the trust in physician, decreased by 0.154 units. There was a statistically significant unique contribution for the communication scale ( $p < .01$ ) and the Medical Mistrust Index ( $p = .04$ ).



The examination of the standardized coefficient Beta (see Table 15), revealed that the communication scale was a stronger predictor in explaining the variance in the trust in physician variable ( $\beta = .38$ ), followed by the Medical Mistrust Index ( $\beta = -.13$ ). Also, the squared partial correlation for the communication scale,  $(0.354)^2 = 0.1253$  indicated that the unique contribution of the communication scale to the prediction of the trust in physician was 12.53%. Moreover, the squared partial correlation for the Medical Mistrust Index,  $(-0.125)^2 = 0.0156$ , implied that the unique contribution of the Medical Mistrust Index to the prediction of trust in physician was 1.56%. However, because none of the predictors have a VIF score greater than ten, this disclosed that multicollinearity was not of specific concern in this case (Dimitrov, 2008, p.196). Specifically, this indicated that each variable (communication scale and medical mistrust) are orthogonal to each other.

### **Summary**

Overall, participants in this study were moderately mistrustful of the healthcare system and the medical staff that worked within the healthcare system, had moderate levels of racial pride towards the Black race, had high levels of religiosity and spirituality, reported moderate levels of positive communication between themselves and their treating physicians, and endorsed “fair” levels of HIV-specific communication between themselves and their treating physicians.

Within this sample there were statistically significant nativity differences only in medical mistrust. That is, foreign-born Blacks endorsed lower levels of medical mistrust compared to United States born Blacks. In addition, racial pride, communication, and nativity each uniquely contributed to predicting the variance in medical mistrust.

Specifically, as communication decreased between the physician and their patient, medical mistrust increased. Medical mistrust also appeared to increase as levels of racial pride increased and as nativity changed from foreign-born to native-born. Further, as medical mistrust decreased amongst participants in this study, the trust that they had towards their physician increased. As communication increased between the patient and his or her physician, the trust that the patient had towards his or her physician also increased. Thus, high levels of racial pride and being born in the United States may be linked to increased rates of medical mistrust, however, positive communication between physicians and their patients appears to be related to higher levels of trust in a physician.

## CHAPTER FIVE

Within the literature on HIV/AIDS, Blacks are disproportionately represented in the HIV/AIDS seropositive population in the United States (CDC, 2011a; Saha, Jacobs, Moore, & Beach, 2010; Weintrob et al., 2009). Although Blacks make up roughly 13% of the United States population (United States Census Bureau, 2013a), 44% of all new HIV seropositive cases in the United States are amongst those who identify as Black (CDC, 2013a). However, within the HIV/AIDS literature race often is only used as a demographic variable and data on cultural differences within this group is overlooked. Furthermore, nativity is repeatedly ignored which could be a concern since there are now large groups of HIV seropositive foreign-born individuals entering the United States (Prosser, Tang, & Hall, 2012) after the 2009 travel ban restriction was lifted (U. S. Department of Health and Human Services, 2009).

Medical mistrust has been identified as a factor that contributes to the difference in cases of HIV/AIDS amongst the Black community compared to any other racial/ethnic group (Thompson et al., 2004). There are many factors that can contribute to mistrust, such as racism, discrimination and historical events (Shoff & Yang, 2012), dating back to slavery (Freimuth, Quinn, Thomas, Cole, Zook, & Duncan, 2001; LaVeist, Nickerson, & Bowie, 2000). These identified factors can have a negative impact on the extent to which Blacks access, receive, and continue with medical care (Ravenell, Whitaker, & Johnson,

2008). Although some research that examines HIV/AIDS amongst the Black community exists (CDC, 2007; Johnson, Hu, & Dean, 2010; LaVeist et al., 2000), no research to date has examined the differences in medical mistrust among native and foreign-born Blacks living with HIV/AIDS.

This study serves as the first empirical investigation to date that examines medical mistrust among native and foreign-born Blacks living with HIV/AIDS and addresses the gap existing within the literature. The three research questions within this study were aimed at opening the dialogue and inquiries on medical mistrust and nativity differences among the HIV/AIDS seropositive Black community in the United States. This chapter provides a forum in which the findings and conclusions that have emerged from this dissertation are thoroughly explored and explained. Comprehensive interpretations of the results as they relate to the purpose of the study are provided. In addition, limitations of this study, implications for counseling, recommendations, and suggestions for future research are discussed.

### **Nativity Differences**

The first research question aimed to determine whether foreign-born and native-born Blacks differed significantly on their level of medical mistrust, racial pride, religiosity, trust in their physician, and communication. The hypothesis posed in this study indicated that there would be nativity differences in medical mistrust, racial pride, religiosity, communication, and trust in one's physicians. Some research has shown that foreign-born HIV seropositive Blacks express higher levels of medical mistrust than their native-born counterparts (Shippee et al., 2013) which could be attributed to the fact that

seropositive foreign-born Blacks are triple stigmatized due to being born in a country outside of the United States, HIV seropositive, and Black (Mahajan et al., 2008; Prosser, Tang, & Hall, 2012). In addition, foreign-born Blacks have been blamed for introducing HIV to the United States (Amon & Todrys, 2008; Day et al., 2006). Further, foreign-born Blacks may grapple with more language barriers when communicating with their physician (Drainoni et al., 2009). Thus, it was assumed that nativity differences would exist among the participants in this study. However, as described below, the hypothesis that there would be nativity differences in medical mistrust, racial pride, religiosity, communication, and trust in one's physicians was only partially supported within this study in that nativity differences (a small effect) were only found in medical mistrust.

**Medical mistrust.** Study findings indicated that there were significant nativity differences only in medical mistrust and not in racial pride, religiosity, trust in one's physician, and communication. Specifically, native-born Blacks within this study endorsed more mistrust of the medical system compared to their foreign-born counterparts, which was contrary to the findings in previous research mentioned above (Shippee et al., 2013). The difference in this study, compared to the findings in other studies, could be attributed to Ogbu's cultural-ecological theory (Ogbu & Simons, 1998). The cultural-ecological theory states that those who are born in the United States are more likely to mistrust systems because of the lack of trust that was present historically (Ogbu & Simons, 1998; Washington, 2006). Foreign-born individuals may have a choice to enter the United States to receive services that they felt may be superior to what they were receiving in their country of origin (Valdez, Valentine, & Padilla, 2013). Further,

foreign-born Blacks may not have experienced racism, prejudice, and discrimination to the extent that native-born Blacks have experienced historically in the United States (Benkert, Peters, Clark, & Keves-Foster, 2006; Ogbu & Simon, 1998) thus their trust of medical systems in the United States may not be relevant to their experiences. Finally, foreign-born Blacks may enter the United States with the willingness to conform to the rules and regulations that have been established in the United States (Ogbu & Simons, 1998) and may be more willing to accept aspects of their medical services that native-born Blacks may feel were inadequate and unjust due to their historical experiences. Read, Emerson, and Tarlov (2005) reported that depending on the country of birth, health related outcomes vary amongst foreign-born Blacks residing in the United States. Specifically, Blacks born in Africa and West Indies and living in the United States have reported better health outcomes, fewer limitations to accessing medical services, and positive outlooks towards their health as compared to their native-born Black counterparts (Read, Emerson, & Tarlov, 2005). Thus, even though some research suggests that foreign-born Blacks may display high levels of medical mistrust, since the majority of foreign-born participants in this study were from Africa and the West Indies, they may have possessed a more favorable outlook on the medical services offered in the United States, thereby endorsing slightly less medical mistrust compared to their native-born counterparts.

Although the mean difference in medical mistrust between native and foreign-born Blacks was statistically significant, it was still small suggesting that both groups overall had high levels of medical mistrust. Thus, although both groups differed slightly

in their levels of medical mistrust, the group differences were not significant enough to support Ogbu's (1998) cultural-ecological theory which states that foreign-born Blacks enter the United States in search of a better life and therefore, would have lower levels of mistrust (Valdez, Valentine, & Padilla, 2013). This finding may be due to the low numbers of foreign-born participants in this study and lack of randomization in the selection of participants. Nonetheless, the results from this study support the fact that Blacks, in general, tend to have high levels of medical mistrust (Boulware et al., 2003; LaVeist et al., 2000), and more importantly, individuals with significant health concerns, such as HIV/AIDS, tend to have higher levels of mistrust towards the healthcare system (Balkrishnan et al., 2003).

**HIV-specific communication.** While the statistical probability of the HIV-specific communication variable was close ( $p = .01$ ), it did not reach statistical significance in this study. Therefore, although foreign born Blacks endorsed less positive HIV-specific communication compared to the US born counterparts, this difference was not statistically significant. The lack of statistical significance may be due to the incongruences between the native and foreign-born samples. That is, roughly a third of the participants were foreign-born and two-thirds were native-born. Since the sample size for foreign-born participants was slightly lower than the recommended 80 (Field, 2009), it is possible that with a few more foreign-born participants, there would have been more power, which potentially could have made the nativity difference in the HIV-specific communication statistically significant.

Nonetheless, the differences between foreign-born and native-born Blacks in HIV-specific communication may be reflective of the fact that foreign-born participants and their physicians may not be comfortable addressing sex related behavior and its effects, alcoholism, and drug use which impacts the prognosis of HIV/AIDS due to the cultural differences, low health literacy by participants, and language barriers (Drainoni, Dekker, Lee-Hood, Boehmer, & Relf, 2009; Singleton & Krause, 2009; Spector & Pinto, 2011). That is, physicians may feel uncomfortable addressing sexual practices due to the physicians' inability to communicate with participants and simply avoid creating more confusion during each medical appointment. Therefore, minimizing the potential language barriers among the foreign-born HIV seropositive Black community may be accomplished by increasing the number of bilingual and bicultural physicians that serve this population (Rudd, Colton, & Schacht, 2000; Singleton & Krause, 2009).

Although previous research has suggested that foreign-born participants have lower levels of communication with their physician due to language barriers (Foley, 2005), besides the HIV-specific communication and medical mistrust, there were no other statistically significant nativity differences in racial pride, religiosity, communication, and trust in physicians. The lack of nativity differences found in this sample may also be due to the length of time that the foreign-born participants in this study have resided in the United States. The participants within this study resided, on average, in the United States for roughly 24 years. Thus, it can be assumed that the foreign-born participants in this study may be more acculturated to the beliefs, customs,



and ways of life within the United States and are familiar with how to navigate the health care system within the United States (Foley, 2005).

### **Predictors of Medical Mistrust**

The second research question aimed to determine whether racial pride, religiosity, communication, nativity, age, and sex served as predictors of medical mistrust. Research has shown that HIV seropositive Blacks with greater religiosity are more inclined to mistrust healthcare systems and medical providers because of a greater reliance on their spirituality, faith, and religious practices (Musa, Schulz, Harris, Silverman, & Thomas, 2009). That is, Blacks, regardless of nativity status, are more likely to believe health related information if received from religious leaders and churches (Musa et al., 2009) and are less likely to believe this information if received from a medical professional (Halbert et al., 2006). Further, individuals with higher levels of racial pride or self-identification towards one's race have been shown to have higher levels of mistrust (Shelton et al., 2010). Lastly, trust is affected by both verbal and nonverbal behaviors of the physician and impacts the level of trust or lack thereof that the patient has towards his or her physician (Cook et al., 2004). Communication, specifically the ways in which HIV/AIDS is discussed between a physician and his or her patient, impacts the patient-physician relationship and in turn affects the level of mistrust/trust that develops (Cook et al., 2014).

The major findings for research question two showed that racial pride, communication, and nativity were significant predictors of medical mistrust. Specifically, as racial pride increased, medical mistrust increased. As the communication between the

physician and the patient improved, medical mistrust decreased. Lastly, as nativity changed from foreign-born to native-born, medical mistrust increased. This was consistent with previous research on racial pride and medical mistrust (Shelton et al., 2010) and research on cultural mistrust and racial pride (Phelps, Taylor, & Gerard, 2001). Prior research has shown that as individuals' levels of racial pride increases, their levels of cultural mistrust increases (Phelps, Taylor, & Gerard, 2001; Townes, Chavez-Korell, & Cunningham, 2009). Although cultural mistrust was not the construct being examined within this study, it is relevant. Cultural mistrust is an overarching term that encompasses medical mistrust. Cultural mistrust is "...the belief acquired by [Blacks], due to past and ongoing mistreatment related to being a member of that ethnic group, that Whites cannot be trusted" (Terrell et al., 2009, p. 299). These past and ongoing mistreatments are applicable to the medical systems and medical professionals within these systems and potentially impacted the levels of medical mistrust held by the participants in this study.

**Racial pride.** The findings from this study suggested that individuals with higher levels of racial pride were more mistrustful of the healthcare system as a whole. However, high levels of racial pride may not be an indicator that participants will completely avoid the healthcare system since the majority of the participants in this study indicated that they trusted their physicians. That is, participants within this study may experience institutional levels of mistrust that are reflective of their suspicion of the medical system and awareness of the historical maltreatment of Blacks, but these suspicions may not necessarily affect participants' views of and interactions with the individuals within these systems. Further, the majority of participants indicated that their

medical staff at their treating facilities were not Black, which is consistent with previous research (American Medical Association, 2010). Although racial non-concordance between patient and physician has been shown to correlate with lower levels of satisfaction and involvement in services (Cooper-Patrick et al., 1999; Drainoni et al., 2009; Spector & Pinto, 2011), it did not appear to affect the trust and satisfaction participants in this study experienced with their physicians. It appears that, for participants in this study, high levels of racial pride may influence participants' views towards the overall healthcare system but not with the individual treatment they received. This finding may have been influenced by the length of time that participants received services from their physician since participants reported receiving HIV/AIDS related services from their healthcare professional for approximately seven years. Nonetheless, the fact that racial pride and medical mistrust were positively related suggests that medical staff members should be aware of the racial and/or cultural nuances surrounding the medical care they provide and how it may be interpreted and received by their patients (Cooper-Patrick et al., 1999; Spector & Pinto, 2011)

**Communication.** In this study, communication predicted levels of medical mistrust such that poor communication levels were related to higher levels of medical mistrust. This finding is consistent with prior research that found that the communication between the physician and the patient impacted trust (Cook et al., 2004). However, in this study, although communication predicted levels of medical mistrust, participants overall indicated that they trust their physician. Thus, for these participants, their

physicians might have been perceived to be more patient-centered and provided adequate information during medical sessions, which may allow for trust to be established.

**Nativity.** Nativity also served as a predictor of medical mistrust in this study which suggests that being born in the United States was related to experiencing higher levels of medical mistrust. In other words, native-born Blacks participating in this study may have internalized the notion that those who have power within medical systems (e.g., Whites) cannot be trusted. These findings could be due to the fact that the social injustices that Blacks in the United States have experienced are uniquely different than that of other Black racial groups that reside outside of the United States (Harris et al., 1996; Sellers et al., 1998) and may ultimately impact how native-born Blacks view medical systems in this country. Blacks residing in the United States have had their rights as human beings denied by the United States Constitution (Sellers et al., 1998) and have experienced medical maltreatment as a result of their racial group identification (Goold, Fessler, & Moyer, 2006).

Besides racial pride, communication, and nativity, there were no other statistically significant predictors of medical mistrust from religiosity, age, and sex. Although previous research has shown that males tend to delay access to medical care and have lower levels of trust towards the medical system (Hammond, Matthews, Mohottige, Agyemang, & Corbie-Smith, 2010), there were no statistically significant sex differences in the levels of medical mistrust amongst this study population. This finding may be due to this study's participants receiving active medical services. Further, age had little to no role in predicting medical mistrust as well. Age may have had no influence on medical

mistrust within this study population because, although not all age groups will know the details about the historical mistreatments of Blacks (e.g. Henrietta Lacks), trust in systems or lack thereof may be a concept passed down from generation to generation and potentially influence participants' perceptions of systems, including the medical system (Goold, Fessler, & Moyer, 2006).

### **Predictors of Trust in one's Physician**

The third research question aimed to understand which factors contributed to explaining participants' trust towards their physician. The final hypothesis posited was that there would be a statistically significant prediction in trust in one's physician from the following variables: communication, religiosity, racial pride, length of services, nativity, medical mistrust, age, and sex. Communication, religiosity, racial pride, length of service, medical mistrust, and nativity are all factors that influence the level of trust that an individual has towards their physician (Cook et al., 2004; Johnson et al., 2004; Spector & Pinto, 2011). The findings from this study indicated that communication and medical mistrust were significant factors in predicting trust in one's physician, which was consistent with previous literature (Cook et al., 2004; Goold, 2001). Specifically as communication improved between the physician and his or her patient, trust increased. Also, as the mistrust that participants' had towards the medical system decreased, trust towards the participants' physicians increased. There was no support within this study's findings to indicate that religiosity, racial pride, length of services, nativity, age, or sex predicted the trust that participants had towards their physician.

**Communication.** Due to the high levels of positive general communication between participants and their physician that were reported within this study, participants were more likely to trust their physician which is consistent with previous research (Hall et al., 2001). The findings within this study indicated that physicians within this study might have provided adequate information during each medical sessions, which may have allowed for participants to understand the extent of his or her illness, associated risks with the illness, and benefits of treatment (Drainoni et al., 2009; Spector & Pinto, 2011), but not adequate information regarding HIV/AIDS specific health information such as sexual risk taking behaviors and substance abuse as identified in research question two.

**Medical mistrust.** The results showed that participants within this study had high levels of trust towards their physicians (interpersonal trust), and could simultaneously experience low levels of medical mistrust (institutional mistrust). Trust involves the acceptance that, in a helpless situation, the patient believes the physician/healthcare organization will act in the best interest of the patient (Hall et al., 2001; Thom et al., 2004), which can be further diminished or enhanced by the interaction (positive or negative) between the patient and physician. Thus, the physician's ability to understand the client's health worries, ability to express the benefits of treatment, and compassionate nature as reported by a majority of participants, may have contributed to the trust that was established.

### **Limitations**

There were several limitations within this study. This study utilized a non-probability convenience sample of HIV/AIDS seropositive Black participants who were

currently receiving HIV/AIDS related treatment in a treatment facility from a large metropolitan area located in the Eastern part of the United States. Therefore, the sample within this study was not representative of the larger population, cannot be generalized to the larger population, and was only applicable to those who participated in this study.

Moreover, participation within this study was voluntary and anonymous.

Participants did not have to sign their name or provide any identifiable information when consenting to participate in this study. This researcher did not track the Internet Protocol (IP) address of participants who completed the online questionnaire. Unfortunately, unbeknownst to the researcher, participants could have completed more than one online questionnaire. Additionally, in attempts to evade illiteracy, each item on the questionnaire was read to participants at both treatment sites. This procedure may have influenced thoughts of anonymity causing some participants to provide desirable answers.

Additionally, due to the analyses of this study, the results should be interpreted with caution. Specifically, within an ANOVA all variances from each group must be equal, however, due to the research being conducted in a real-world setting, it was extremely difficult to ensure that each group could be equal (Dimitrov, 2008). Since there were significantly fewer foreign-born HIV/AIDS seropositive Blacks participating in this study, it is difficult to say that the results represent the general HIV/AIDS seropositive Black population.

This study is unable to determine a cause and effect relationship between HIV/AIDS seropositive Blacks' medical mistrust and trust towards their physicians. Specifically, it cannot be said that nativity, age, sex, religiosity, racial pride, or

communication caused or effected the development of medical mistrust or trust in one's physician. Within a regression analysis, only the relationships between the predictor variables and the outcome variable can be exposed (Dimitrov, 2008). It is highly possible that there are other factors that influence the trust that patients have towards their physician.

**Instruments.** There were a few limitations to the instruments used. The instruments used within this study were the best instruments available, the instruments lacked precision to make specific reliable detection. Specifically, the analyses conducted within this study were linear, however, the effect of the analyses were curvilinear. That is, theoretically, a ceiling exists which caused the results to hit an asymptote. However, due to the specific analyses that were executed within this study, this researcher was unable to determine where the theoretical ceiling lied. Further, only a snapshot of the linear analysis could be provided when interpreting the results. The researcher utilized linear analysis since it was the most appropriate approach to use given the precision and background knowledge of the scales and subscales.

### **Implication for Counseling and Medical Services**

The transformation of individuals' perceptions of HIV/AIDS from a death sentence to a manageable chronic disease has promoted a shift in focus to addressing the many psychosocial factors that affect this population. The current study's results have clinical and counseling implications for counseling and HIV medical professionals. Although it was found that a majority of participants were not interested in seeking psychological or counseling services, the findings underscore the need for the use of



culturally competent mental health service provision to those who are diagnosed with HIV and/or AIDS, specifically, since counseling has been identified as an integral part of HIV/AIDS treatment and care (Kanekar, 2011). Since participants, overall, endorsed moderate levels of medical mistrust, endorsed high levels of racial pride which also was related positively to medical mistrust, and participants seemed less willing to use counseling services as a coping strategy for their HIV/AIDS diagnosis, it appears that from a systemic perspective, researchers, medical staff, and counselors should try to understand HIV seropositive individuals' resistance to accessing and continuing to utilize medical services and related counseling services, to identify the root of medical mistrust, and to use effective culturally relevant counseling techniques to address mistrust (Kanekar, 2011). Lastly, counseling and medical services should be integrated and medical staff should encourage counseling services during participants' medical visits.

**Medical mistrust.** Since medical mistrust has been identified as a factor that prevents Blacks with significant health concerns from accessing medical services (Hammond et al., 2010; Shelton et al., 2010), identifying the root of medical mistrust can assist in tailoring culturally specific intervention and prevention programs to increase HIV testing, access, receiving, and continuing with HIV/AIDS related medical treatment and support services (Bogart et al., 2010).

**Cultural competency.** At the center of professional counselors' agendas when working with the HIV/AIDS seropositive Black population should be competent care that helps shed light on the sociohistorical events that may influence their client's health and behavior. Cultural competency is defined as the counselor or provider's ability to

adequately provide services, use their professional skills, aptitude, and proficiency when working with a diverse population (Armstrong et al., 2008; Whaley & Davis, 2007). Specifically, Sue (1998), identifies cultural competency as the provider or therapist's ability to identify, assess, and test hypothesis, be cognitively aware that participants are individuals but yet are a part of a large cultural group, and have culturally specific resources that include being well-informed and proficient to work with individuals' from various cultures.

Cultural competent strategies that professional counselors can use during session include providing culturally specific language when delivering intervention strategies and assessing clients (Sue, Zane, Nagayama Hall, & Berger, 2009), assessing from which status of racial identity participants are operating (Parham & Helms, 1985; Sue et al., 2009), assessing participant's medical mistrust (LaVeist et al. 2009), introducing culturally relevant information such as myths associated with "race-related rape" which provide inadequate and false information regarding sexual risk taking behaviors and messages regarding the lack of trust towards systems (Sue et al., 2009), and addressing acculturation and adaption concerns for foreign-born Blacks which may influence how they interpret psychosocial stressors related to racism (Bemak & Chung, 2008). Further, professional counselors should be trained in culture specific competence training to include understanding the historical context of Blacks and HIV/AIDS, and its effect on this community.

Lastly, professional counselors can use assessment tools such as the cultural genogram, which visually provides information regarding participants family lineage and

can be used to focus on intergenerational patterns and message passed along from generation to generation (Boyd-Franklin, 2003). Genograms provide knowledge and awareness to the client about his or her strengths, views, and rituals within his or her family (Boyd-Franklin, 2003) and can serve as an information tool for counselors. Additional strategies that counselors can use are exploring participants' thoughts about receiving HIV/AIDS related services, motivational interviewing to assess client's readiness to seek HIV/AIDS related services, addressing the specific needs of clients (e.g. lack of transportation, lack of insurance, stigma), and providing psychoeducation and the health and psychosocial benefits of seeking medical treatment early (Amon & Todrys, 2008; Bogart et al., 2004; Kanekar, 2011; Robinson et al., 2012).

**Coping and religiosity.** Based on the findings from this study, a majority of participants reported having a high sense of religious or spiritual affiliations and specified that religion was a preferred coping mechanism for dealing with their HIV/AIDS status. This finding is consistent with previous research which indicated that Blacks, generally have high levels of religiosity and spirituality, especially when faced with significant health concerns (Miller, 2005; Miller & Thoresen, 2003). Since many participants reported attending church and praying more than any other coping mechanism, it could be important for counselors to examine the role of religion in their clients' lives and to determine whether or not it is used as a coping strategy. Bringing the church culture, spirituality, and religion into HIV treatment and care services could be an important factor when working with the HIV/AIDS seropositive Black community. Specifically, professional counselors may want to consider utilizing prayer, meditation, spiritual

schemas, reading of scriptures, playing spiritual music, and spiritual imagery during counseling sessions (Dalmida, 2006). In addition, counselors can work alongside religious and spiritual leaders as a way to link an individual's faith, counseling, and HIV/AIDS treatment and care (Mueller, Plevak, & Rumman, 2001).

Participants also indicated that talking primarily to their friends and family regarding their diagnosis was another way in which they coped with their HIV/AIDS diagnosis. These results could be attributed to the fact that within Black culture, the extended family network is seen as an important source of support (Lincoln, Taylor, & Chatters, 2003). We can assume from this finding that HIV/AIDS was a conversation that many HIV/AIDS seropositive individuals were willing to have with those who were close to them. Thus, incorporating the individual's family members into counseling sessions could be beneficial and essential when working with the HIV/AIDS seropositive Black community (Greer, 2011). Lastly, research has shown that barriers to seeking counseling services include stigma associated with having a mental illness and the shame associated with seeking services from a counselor (Day, Edgren, & Eshleman, 2007). Counselors and HIV medical professionals should join forces and foster positive views of counseling services which can perhaps aid in de-stigmatizing counseling services (WHO, 2008).

**Communication.** Results from this study suggested that as communication regarding one's health and HIV/AIDS decreased, medical mistrust increased. Therefore, counselors could potentially assist with increasing positive communication between a physician and his or her client. Counselors could use role play techniques with their clients and/or physicians to model effective communication skills, which could

potentially decrease the level of mistrust that clients have towards their physicians.

Effective communication can consist of explaining test results in a way that the client can understand, clear and concise statements, and allowing enough time for clients to ask questions. Professional counselors who work with clients on addressing their difficulties with communicating with their physician can facilitate the development of the skills needed to communicate effectively and the techniques to overcome these barriers (Sue et al., 1999).

Professional counselors should encourage open communication and interactive discourse to help clients work through their conflicts when it arises. This is especially important when working with the HIV/AIDS population because research has shown that increased communication can help mediate the effects of mistrust (Cook et al., 2004) and increase patient's engagement in HIV-related care (Flicker et al., 2013). Professional counselors should allow collaboration in which the counselor and the client are both working towards the same outcomes and goals. Due to the lack of training that many professional counselors have when working with the HIV/AIDS population (WHO, 2008), allowing for the client to share and shed light on their struggles and concerns, as well as serve as an expert on their health, could help decrease the levels of mistrust that clients' have in their counselors.

**Racial pride and foreign-born concerns.** Racial pride within this study was shown to be related to increased levels of medical mistrust. Racial pride is defined as the manner in which individuals identify with their socially ascribed racial groups (Landrine & Klonoff, 1995). Racial pride has been linked to various psychological outcomes

including increased self-worth, buffering the effects of discrimination and emotional distress (Sellers & Shelton, 2003), and has been shown to impact medical mistrust (Shelton et al., 2010). Thus, given that racial pride was positively correlated with the higher levels of medical mistrust, it could be beneficial for counselors to assess the extent to which clients have internalized their racial identity, in order to understand their levels of trust in their medical system and to effectively work through these concerns.

Professional counselors should first understand the prejudices and racism that client's experience and ensure that the interventions used are culturally sensitive to this population. When working with this population, many counselors will be exposed to those from various cultures, which may differ substantially from their own. Professional counselors may be faced with a foreign-born HIV seropositive individual and his or her legal status, and health barriers, which may be contrary to the counselors' beliefs. Further, many foreign-born participants who are undocumented may have fears of seeking medical help due to the fear of deportation or other adverse legal consequence. Counselors must be aware of the various rights, laws, and regulations that vary from state to state regarding disclosure and immigration (Robinson et al., 2012) and serve as an advocate for their clients (Chung, Bemak, Ortiz, & Sandoval-Perez, 2008). Counselors should, as always, be an advocate for their clients, question medical practices that adversely affect those that he or she serves, and take action when necessary.

### **Recommendations for Prevention and Practice for HIV Professionals**

As shown by this research study and previous research, participants indicated that HIV-specific communication was minimal and often uncomfortable between physicians

and their clients (Drainoni, Dekker, Lee-Hood, Boehmer, & Relf, 2009; Spector & Pinto, 2011). It is recommended that physicians, medical staff, and professional counselors are trained on how to address HIV/AIDS related health topics appropriately. Lack of communication between patients and physicians is vital when attempting to increase trust of physician and decrease stigma. Based on the findings of this study, the lack of HIV-specific positive communication between the physician and patient suggested that HIV/AIDS continues to be a taboo topic even with health professionals. Improving one's communication with their physician and other professionals providing HIV/AIDS related care, can improve the levels of mistrust that a Black patient has towards the medical system and staff members within each medical facilities.

There are many counseling prevention strategies that can be addressed based on the findings of this study. Many participants within this study indicated that they were single followed by either being in a relationship or married. Individual, group, and couples therapy can be used to provide psychoeducation to participants to learn how to mutually protect each other, which can reduce the chances of infecting a seronegative partner or superinfecting a partner who is currently HIV/AIDS seropositive (The National Institute of Mental Health Multisite HIV/STD Prevention Trial for African American Couples Group, 2008). There are many benefits of having participants attend prevention counseling sessions to include increasing closeness and trust, decrease gender power imbalances within relationships, and increase communication and negotiation skills regarding HIV risks and sexual activity (El-Bassel et al., 2003).

To address the systemic barriers that influence the high levels of medical mistrust that Blacks have towards the medical system is to have more Black medical professionals (e.g. physicians, nurse practitioners, social workers, counselors, etc.) providing medical care to HIV/AIDS seropositive Blacks. Research has shown that by having racial concordance between the patient and their attending physician and medical staff improves trust and patient satisfaction (LaVeist & Nurur-Jeter, 2002; Phelps et al., 2001; Thom, 2000).

Lastly, Kanekar (2011) indicated that counselors, specifically prevention counseling, should be involved in all aspects of the HIV/AIDS services to include pre- and post- testing counseling. Prevention counseling should be used as a primary means of risk reduction amongst the HIV/AIDS seropositive community. Risk reduction should include speaking with client's about sexual risk taking behaviors, barriers to sexual safety, and planning for safer sex. Pre-testing counseling should consist of providing therapeutic services to encourage client's to seek routine HIV/AIDS testing and services early on, link client's with appropriate medical services, and preparing clients on what to expect during and after receiving their HIV/AIDS results. Post-testing counseling should include individual, couple, family, and/or group counseling to assist clients in increasing their social support, aide clients in partner notification if necessary, psychoeducation, and planning for a safer and healthier lifestyle. Prevention counseling can assist in the destigmatization of being HIV/AIDS seropositive and assist in improving or stabilizing the individual's psychosocial well-being (Kanekar, 2011).



## **Future Research**

During the course of this study, there were several areas found by this researcher that could be addressed by future research including further examination of medical mistrust. Previous research has shown that medical mistrust is a factor that prevents Blacks from accessing or remaining in services due to their mistrust of the medical system (LaVeist, Nickerson, & Bowie, 2000; Ravenell, Whitaker, Johnson, 2008). However, no research to date has examined the origin of medical mistrust and other factors that contribute to Blacks' medical mistrust.

The majority of research on medical mistrust within the HIV/AIDS seropositive Black community has used quantitative methodology (Bogart et al., 2010; Hoyt et al., 2012; LaVeist, Nickerson, & Bowie, 2000). Future research using qualitative research methodology; specifically interviews to obtain participants' perspective on what factors contribute to the development of mistrust may be beneficial (Maxwell, 2013). Qualitative research can provide personal histories, experiences, and comprehensive explorations, which can be obtained by asking open-ended questions from in-depth interviews (Maxwell, 2013). Information that is obtained from qualitative interview provides more individualized responses, whereas quantitative research aggregates the information to describe a population as a whole (Maxwell, 2013).

Furthermore, research should examine cultural differences such as language barriers and racial identity status as it relates to nativity and medical mistrust amongst Blacks living with HIV/AIDS. Racial pride is important to examine since this study and other research has shown that those who have higher levels of racial pride also have

higher levels of medical mistrust (Shelton et al., 2010). Identifying which status of racial identity correlates with higher levels of medical mistrust within the HIV/AIDS seropositive native-born and foreign-born community can assist in appropriately addressing interventions to decrease medical mistrust. Also, use of an acculturation measure may also provide more information as to how foreign-born individuals cope with navigating the medical health systems in the United States. In addition, identifying intervention and prevention strategies that incorporate religion and spirituality has been shown to increase the amount of HIV/AIDS information received from Black HIV/AIDS seropositive individuals, specifically if received from faith-based organizations (Szaflarski et al., 2013). Lastly, an examination of the effects of counseling amongst those who have medical mistrust should be conducted to determine whether various forms of counseling services (e.g. group, couple, and individual therapy) and interventions can be effective in decreasing the level of medical mistrust amongst this population.

### **Summary**

Results from this study support minor nativity differences in HIV/AIDS seropositive individuals with respect to their levels of medical mistrust. These minor differences may have been minimized due to the low numbers of foreign-born Blacks who participated in this study. Nonetheless, this data suggests that native-born participants may be more likely to mistrust the medical systems at a higher rate than their foreign-born counterparts. Further, high levels of racial pride and low levels of communication also seem to play a role in the level of trust that participants have towards

their treating physician and the medical system. That is, higher levels of racial pride may increase the mistrust that participants had towards the medical system, yet better communication between participants and their physician may increase the trust that participants had towards their physician. Thus, it appears that medical staff and counselors working with HIV/AIDS seropositive individuals should provide culturally relevant services; particularly providing positive communication. Staff should also be aware that Black HIV/AIDS seropositive individuals may lean more towards using spirituality as a coping mechanism and may be more adverse towards seeking services from a counselor or psychologist. Since counseling is seen as an integral part of the treatment for HIV/AIDS seropositive participants, it is evident that counselors must seek to incorporate culturally relevant methods of service delivery if they desire to work with this population. Although the findings from this study cannot be generalized, the information provided can be used to inform researchers, counselors, and medical staff about potential outcomes for the native and foreign-born HIV/AIDS seropositive Blacks, and not just the participants within this study.

## APPENDIX A

### IRB Approval Letter



#### Office of Research Integrity and Assurance

Research Hall, 4400 University Drive, MS 6D5, Fairfax, Virginia 22030  
Phone: 703-993-5445; Fax: 703-993-9590

DATE: January 9, 2014

TO: Regine Talleyrand, Ph.D.  
FROM: George Mason University IRB

Project Title: [489157-2] The Examination of Medical Mistrust among Native and Foreign-born Blacks Living with HIV/AIDS

SUBMISSION TYPE: Amendment/Modification

ACTION: DETERMINATION OF EXEMPT STATUS

DECISION DATE: January 9, 2014

REVIEW CATEGORY: Exemption category #2

Thank you for your submission of Amendment/Modification materials for this project. The Office of Research Integrity & Assurance (ORIA) has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

Please remember that all research must be conducted as described in the submitted materials.

Please note that any revision to previously approved materials must be submitted to the ORIA prior to initiation. Please use the appropriate revision forms for this procedure.

If you have any questions, please contact Karen Motsinger at 703-993-4208 or [kmotsing@gmu.edu](mailto:kmotsing@gmu.edu). Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within George Mason University IRB's records.

## APPENDIX B

Jupiter Flyer

Do You Want to Share Your Thoughts on the  
Medical Services that You Are Receiving to  
Improve Your Quality of Care?

If so, consider completing a confidential  
survey in the library with a doctoral  
student from George Mason University.

APPROVED  
489157-6  
George Mason University

## APPENDIX C

### Triton Script

Hello, my name is \_\_\_\_\_ and I'm an intern with Triton.

**A.** I would like to speak with [NAME OF ADULT]

**ONLY IF THE ANSWERING INDIVIDUAL ASKS WHAT THE CALL IS FOR:**

We are doing a study of how people feel about their doctors, hospitals, and the healthcare system. The goal of this study is to use this information to help hospitals and doctors serve their patients better.

**Re-introduce yourself to the adult.**

Hello, my name is \_\_\_\_\_ and I'm an intern from Triton. I am working with a student from George Mason University by the name of Winifred Betts-Campbell who is interested in studying how people feel about their doctors, hospitals, and the healthcare system. The goal of this study is to use this information to help hospitals, doctors, and our agency better improve medical services amongst those who are HIV positive. The questionnaire will take less than 20 minutes to complete and you will receive a \$5 Walmart gift card if you choose to complete the survey. To qualify, you must be self-identify as Black/African American, be at least 18 years of age, and currently receive HIV/AIDS related services.

**Go to item B.**

**B. INTERVIEWER: GO TO CONSENT FORM AND CONSENT PATIENT.**

Q1) Are you willing to be involved in this study?

- 1 – yes
- 2 – No

**If “yes” continue.**

**If “no” thank the respondent and end the interview.**

If willing but not now, schedule appointment.

Day of week (Monday-Friday) \_\_\_\_\_

Date (Month/Day/Year) \_\_\_\_\_

Time (AM or PM) \_\_\_\_\_

Verify telephone number and record here \_\_\_\_\_

Continue for all other respondents.

**Next, I would like to ask you a few questions about how you feel about healthcare organizations. When I say healthcare organizations, I am not asking about an individual doctor, nurse, or any other person. I am asking about organizations where you might get HIV related health services, like a hospital or a clinic. Please listen to the following statements carefully. For each one, tell me whether you strongly disagree, disagree, agree or strongly agree.**

1. You'd better be cautious when dealing with health care organizations (i.e. hospitals)

Circle one:      strongly disagree      disagree      agree      strongly agree

2. African American/Black patients have sometimes been deceived or misled by health care organizations (i.e. hospitals)

Circle one:      strongly disagree      disagree      agree      strongly agree

3. When health care organizations (i.e. hospitals) make mistakes they usually cover it up

Circle one:      strongly disagree      disagree      agree      strongly agree

4. Health care organizations (i.e. hospitals) have sometimes done harmful experiments on African American/Black patients without their knowledge

Circle one:      strongly disagree      disagree      agree      strongly agree

5. Health care organizations (i.e. hospitals) don't always keep your information totally private

Circle one:      strongly disagree      disagree      agree      strongly agree

6. Sometimes I wonder if health care organizations (i.e. hospitals) really know what they are doing

Circle one:      strongly disagree      disagree      agree      strongly agree

7. Mistakes are common in health care organizations (i.e. hospitals)

Circle one:      strongly disagree      disagree      agree      strongly agree

8. If you have heard about health care organizations deceiving or misleading African American/Black patients, from whom did you receive this information? (Check all that apply)

- |                                                                  |                                              |
|------------------------------------------------------------------|----------------------------------------------|
| <input type="checkbox"/> Family                                  | <input type="checkbox"/> Church              |
| <input type="checkbox"/> Friends                                 | <input type="checkbox"/> Personal Experience |
| <input type="checkbox"/> Media (movies, television, news, radio) | <input type="checkbox"/> Historical Events   |
|                                                                  | <input type="checkbox"/> Other _____         |

**Now I'm going to ask you some questions about your faith, spirituality, and thoughts about your race. For each statement that I read, please tell me whether you strongly disagree, disagree, or if you agree or strongly agree.**

9. I talk openly about my faith with others.

Circle one:      strongly disagree      disagree      agree      strongly agree

10. I often read religious books, magazines, or pamphlets.

Circle one:      strongly disagree      disagree      agree      strongly agree

11. I often watch or listen to religious programs on television or radio.

Circle one:      strongly disagree      disagree      agree      strongly agree

12. My spiritual beliefs are the foundation of my approach to life.

Circle one:      strongly disagree      disagree      agree      strongly agree

13. I am often aware of the presence of a higher being in my life.

Circle one:      strongly disagree      disagree      agree      strongly agree



14. I have a personal relationship with a higher being.

Circle one:      strongly disagree      disagree      agree      strongly agree

15. When I am ill, I pray for healing.

Circle one:      strongly disagree      disagree      agree      strongly agree

16. I pray often.

Circle one:      strongly disagree      disagree      agree      strongly agree

17. I rely on a higher being to keep me in good health.

Circle one:      strongly disagree      disagree      agree      strongly agree

18. African American/Black people make America strong.

Circle one:      strongly disagree      disagree      agree      strongly agree

19. The individuals I respect most in life are African American/Black.

Circle one:      strongly disagree      disagree      agree      strongly agree

20. Being African American/Black is an important part of who I am.

Circle one:      strongly disagree      disagree      agree      strongly agree

21. I feel a strong connection to other African American/Black people.

Circle one:      strongly disagree      disagree      agree      strongly agree

22. Racial pride is important for developing strong African American/Black families.

Circle one:      strongly disagree      disagree      agree      strongly agree

23. I think everybody should be taught about how African American/Black people helped to build America.

Circle one:      strongly disagree      disagree      agree      strongly agree

24. Black people should keep up with issues that are important to the African

American/Black community.

Circle one:      strongly disagree      disagree      agree      strongly agree

**Now I'd like you to think about the doctor who takes care of your HIV. For each statement, please respond by saying N/A, poor, fair, good, very good, or excellent**

How is the medical staff who takes care of your HIV at:

25. Explaining the results of tests in a way that you understand?

Circle one:      poor      fair      good      very good      excellent

26. Giving you facts about the benefits and risks of treatment?

Circle one:      poor      fair      good      very good      excellent

27. Telling you what to do if certain problems or symptoms occur?

Circle one:      poor      fair      good      very good      excellent

28. Demonstrating caring, compassion, and understanding?

Circle one:      poor      fair      good      very good      excellent

29. Understanding your health worries and concerns?

Circle one:      poor      fair      good      very good      excellent

30. Talking with you about your sex life?

Circle one:    n/a      poor      fair      good      very good      excellent

31. Asking you about stresses in your life that may affect your health?

Circle one:    n/a      poor      fair      good      very good      excellent

32. Asking about problems with alcohol?

Circle one:    n/a      poor      fair      good      very good      excellent

33. Asking about problems with street drugs like heroin and cocaine?

Circle one:    n/a      poor      fair      good      very good      excellent

**This last section asks about your background information. Please respond by telling me the option that best describes you in each category.**

**34. What is your sex?**

☐ Male

☐ Female

**35. What is your age?** \_\_\_\_\_

**36. What is your sexual orientation?**

☐ Heterosexual or straight

☐ Gay or lesbian

☐ Bisexual

☐ Decline to answer

**37. What is your marital status?**

☐ Single

☐ Married

☐ Divorced

☐ In a relationship

☐ Widowed

**38. How do you describe yourself? (Please mark the option that best describes you, if other, please specify)**

☐ Black

☐ African

☐ Black American

☐ African American

☐ West Indian Black

☐ Other: \_\_\_\_\_

**39. What is the highest level of education completed?**

☐ Grades 1-6

☐ Grades 7-8

☐ Grades 9-12

☐ Some College

☐ College Graduate

☐ Some Graduate Level School

☐ High School Graduate

☐ Some Technical/Professional Degree

☐ Master's Degree

☐ Doctoral Degree

**40. What is your insurance status?**

☐ Uninsured

☐ Medicaid

☐ Other: \_\_\_\_\_

☐ Medicare

☐ Private Insurance

**41. Were you born in the United States?**

☐ No.

If no, in what country were you born? \_\_\_\_\_ **AND** for how long have you lived in the United States? \_\_\_\_\_

☐ Yes

If yes, in what state: \_\_\_\_\_ **AND** for how long have you lived in Virginia? \_\_\_\_\_

42. **Were your parent born in the United States?**  
☐ No. ☐ Yes  
 If no, in what country were your If yes, in what state:  
 parents born? \_\_\_\_\_ \_\_\_\_\_ **AND** for how long  
**AND** for how long have they lived in have they lived in Virginia?  
 the United States? \_\_\_\_\_ \_\_\_\_\_
43. **Did you recently change service provider?**  
☐ No ☐ Yes
44. **How long have you received services from Triton for your HIV/AIDS?**  
 \_\_\_\_\_
45. **What is your current diagnosis?**  
☐ HIV ☐ AIDS
46. **For how many years have you known about your HIV diagnosis?** \_\_\_\_\_
47. **For how many years have you known about your AIDS diagnosis?** \_\_\_\_\_
48. **When did you seek help for your HIV/AIDS diagnosis?**  
☐ Immediately ☐ Within 1 year  
☐ Within 6 months ☐ After 1 year
49. **Besides your medical staff, who knows about your HIV/AIDS status? (check all that apply)**  
☐ No one ☐ Other relatives  
☐ Mother ☐ Friends  
☐ Father ☐ Pastor or other church members  
☐ Sister ☐ Employer  
☐ Brother ☐ Other: \_\_\_\_\_
50. **Is your physician/nurse practitioner that manages your HIV/AIDS treatment African American/Black?**  
☐ No ☐ Yes
51. **Is your nurse/social worker at Triton African American/Black?**  
☐ No ☐ Yes
52. **Are the other staff (secretary, pharmacist, etc.) at Triton African American/Black?**  
☐ No ☐ Yes
53. **To what extent do you trust your physician that manages your HIV/AIDS?**

- |                                                              |                                                          |
|--------------------------------------------------------------|----------------------------------------------------------|
| <input type="checkbox"/> I do not trust my physician at all. | <input type="checkbox"/> I trust my physician.           |
| <input type="checkbox"/> I do not trust my physician.        | <input type="checkbox"/> I trust my physician very much. |
| <input type="checkbox"/> I neither trust nor distrust my     |                                                          |

**54. How do you cope with your current diagnosis?**

- |                                                         |                                                                                             |
|---------------------------------------------------------|---------------------------------------------------------------------------------------------|
| <input type="checkbox"/> I pray/go to church            | <input type="checkbox"/> I use substance (illegal drugs, prescription drugs, alcohol, etc.) |
| <input type="checkbox"/> I see a counselor/psychologist | <input type="checkbox"/> I over/under eat                                                   |
| <input type="checkbox"/> I talk to my friends/family    | <input type="checkbox"/> Other: _____                                                       |
| <input type="checkbox"/> I am not coping                |                                                                                             |

**55. How is your coping technique working for you? (Please circle the answer that is closest to your opinion)**

Not	-----	Neither	-----	Working					
working				well					
1	2	3	4	5	6	7	8	9	10

**56. Are you willing to see a counselor/psychologist regarding any health concerns?**

- |                             |                              |
|-----------------------------|------------------------------|
| <input type="checkbox"/> No | <input type="checkbox"/> Yes |
|-----------------------------|------------------------------|

If yes, would it make a difference if the counselor was African American/Black?

- |                             |                              |
|-----------------------------|------------------------------|
| <input type="checkbox"/> No | <input type="checkbox"/> Yes |
|-----------------------------|------------------------------|

We have finished with all of the questions. Thank you very much for your participation in this study. Have a great day!

## **APPENDIX D**

### **Online Advertisement**

Hello, my name is Winifred Betts-Campbell and I am a doctoral candidate at George Mason University's College of Education and Human Development. I am currently conducting a study to gather information on your medical experiences. This survey will take roughly 20 to 30 minutes to complete. In order to participate in this study, you must self-identify as Black/African American, be at least 18 years of age, reside in the United States, and currently receive HIV/AIDS related medical services. The data collected in this study will be confidential and anonymous. If you are interested or know anyone who is interested in completing this survey, please have him or her complete the questionnaire by clicking on the following link: **CLICK HERE**

If the link does not work cut and paste the following link to your web browser:

<https://www.surveymonkey.com/s/5TLFF5N>

## **APPENDIX E**

### ***The Examination of Medical Mistrust among Native and Foreign-born Blacks living with HIV/AIDS***

#### **INFORMED CONSENT FORM-JUPITER**

##### **RESEARCH PROCEDURES**

This research is being conducted to learn more about your experience with medical services. If you agree to participate, you will be asked to complete a 20 to 30-minute survey.

##### **RISKS**

There are no foreseeable risks if you participate in this study.

##### **BENEFITS**

There are no benefits to you as a participant other than to further research to develop an in-depth understanding of the experiences that lead to developing medical mistrust in order to gain insight into this phenomenon that can be useful for the development of counseling and educational interventions, and serve as the basis for further research.

##### **CONFIDENTIALITY**

The information collected in this study will be confidential. The principal investigator will only have access to the information collected in this survey. The principal investigator will not have access to your private health information. No identifiable information such as your date of birth will be collected. Your name will not be included on the surveys; a code will be placed on the bottom right corner of the survey; the researcher will not be able to link your survey to your identity. The survey will be kept in a locked drop box located at Jupiter. The key to the locked cabinet will be kept separately. Others will not have access to the participant's information.

##### **PARTICIPATION**

Your participation is voluntary, and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no

penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party. In return for your time, you will be given a \$5.00 gift card to Walmart for participating in this study. Only those who answer all questions will receive the gift card. Gift cards will be handed to you after completing all items on the questionnaire.

## **CONTACT**

This research is being conducted by Winifred Betts-Campbell, a student in the College of Education and Human Development at George Mason University. She may be reached at 703-725-7551 for questions or to report a research-related problem. The student's faculty advisor is Dr. Regine M. Talleyrand and she can be reached at 703-993-4419. You may contact the George Mason University Office of Research Integrity & Assurance at 703-993-4121 if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

## **CONSENT**

By checking the YES box indicates that I have read this form and agree to participate in this study.

☐ Yes, I agree

If yes, please proceed to the other sections of this questionnaire.

☐ No I do not agree

If no, please place this form into the drop box located at the front of this facility.



## **APPENDIX F**

### ***The Examination of Medical Mistrust among Native and Foreign-born Blacks living with HIV/AIDS***

#### **INFORMED CONSENT FORM- Triton**

##### **RESEARCH PROCEDURES**

This research is being conducted to learn more about your experience with medical services. If you agree to participate, you will be asked to complete a 20 to 30-minute survey.

##### **RISKS**

There are no foreseeable risks if you participate in this study.

##### **BENEFITS**

There are no benefits to you as a participant other than to further research to develop an in-depth understanding of the experiences that lead to developing medical mistrust in order to gain insight into this phenomenon that can be useful for the development of counseling and educational interventions, and serve as the basis for further research.

##### **CONFIDENTIALITY**

The information collected in this study will be confidential. The principal investigator will only have access to the information collected in this survey. The principal investigator will not have access to your private health information. No identifiable information such as your date of birth will be collected. Your name will not be included on the surveys; a code will be placed on the bottom right corner of the survey; the researcher will not be able to link your survey to your identity. The survey will be kept in a locked drop box located at Triton. The key to the locked cabinet will be kept separately. Others will not have access to the participant's information.

##### **PARTICIPATION**

Your participation is voluntary, and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no

penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party. In return for your time, you will be given a \$5.00 gift card to Walmart for participating in this study. Only those who answer all questions will receive the gift card. Those who complete the survey on-site will receive the gift card after completion. Those who complete the survey via phone will receive the gift card by mail approximately 6 weeks after completing this survey.

## **CONTACT**

This research is being conducted by Winifred Betts-Campbell, a student in the College of Education and Human Development at George Mason University. She may be reached at 703-725-7551 for questions or to report a research-related problem. The student's faculty advisor is Dr. Regine M. Talleyrand and she can be reached at 703-993-4419. You may contact the George Mason University Office of Research Integrity & Assurance at 703-993-4121 if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

## **CONSENT**

By checking the YES box indicates that I have read this form and agree to participate in this study.

☐ Yes, I agree

If yes, please proceed to the other sections of this questionnaire.

☐ No I do not agree

If no, please place this form into the drop box located at the front of this facility.

## **APPENDIX G**

### ***The Examination of Medical Mistrust among Native and Foreign-born Blacks living with HIV/AIDS***

#### **INFORMED CONSENT FORM-Online**

##### **RESEARCH PROCEDURES**

This research is being conducted to learn more about your experience with medical services. If you agree to participate, you will be asked to complete a 20 to 30-minute survey.

##### **RISKS**

There are no foreseeable risks if you participate in this study.

##### **BENEFITS**

There are no benefits to you as a participant other than to further research to develop an in-depth understanding of the experiences that lead to developing medical mistrust in order to gain insight into this phenomenon that can be useful for the development of counseling and educational interventions, and serve as the basis for further research.

##### **CONFIDENTIALITY**

The information collected in this study will be confidential. The principal investigator will only have access to the information collected in this survey. The principal investigator will not have access to your private health information. No identifiable information such as your date of birth will be collected. Your name will not be included on the surveys. While it is understood that no computer transmission can be perfectly secure, reasonable efforts will be made to protect the confidentiality of your transmission.

##### **PARTICIPATION**

Your participation is voluntary, and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party. In return for your time, you will be given a \$5.00 gift card to Walmart for participating in this study. Only those who answer all questions will receive the gift

card.

## **CONTACT**

This research is being conducted by Winifred Betts-Campbell, a student in the College of Education and Human Development at George Mason University. She may be reached at 703-725-7551 for questions or to report a research-related problem. The student's faculty advisor is Dr. Regine M. Talleyrand and she can be reached at 703-993-4419. You may contact the George Mason University Office of Research Integrity & Assurance at 703-993-4121 if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

## **CONSENT**

By checking the YES box indicates that I have read this form and agree to participate in this study.

☐ Yes, I agree

☐ No I do not agree

## APPENDIX H

### MEDICAL MISTRUST INDEX

**General instruction:** For the following sections, please read each question and circle the answer that is closest to your opinion.

For example if you agree with the statement then circle:

strongly disagree      disagree      agree      strongly agree

For example if you strongly disagree with the statement then circle:

strongly disagree      disagree      agree      strongly agree

1. You'd better be cautious when dealing with health care organizations (i.e. hospitals)

Circle one:      strongly disagree      disagree      agree      strongly agree

2. African American/Black patients have sometimes been deceived or misled by health care organizations (i.e. hospitals)

Circle one:      strongly disagree      disagree      agree      strongly agree

3. When health care organizations (i.e. hospitals) make mistakes they usually cover it up

Circle one:      strongly disagree      disagree      agree      strongly agree

4. Health care organizations (i.e. hospitals) have sometimes done harmful experiments on African American/Black patients without their knowledge

Circle one:      strongly disagree      disagree      agree      strongly agree

5. Health care organizations (i.e. hospitals) don't always keep your information totally private

Circle one:      strongly disagree      disagree      agree      strongly agree

6. Sometimes I wonder if health care organizations (i.e. hospitals) really know what they are doing

Circle one:      strongly disagree      disagree      agree      strongly agree

7. Mistakes are common in health care organizations (i.e. hospitals)

Circle one:      strongly disagree      disagree      agree      strongly agree

8. If you have heard about health care organizations deceiving or misleading African American/Black patients, from whom did you receive this information? (Check all that apply)

☐ Family

☐ Friends

☐ Media (movies, television, news, radio)

☐ Church

☐ Personal Experience

☐ Historical Events

☐ Other \_\_\_\_\_

## APPENDIX I

### RELIGIOSITY SUBSCALE

**Directions:** Please read each question and circle the answer that is closest to your opinion.

9. I talk openly about my faith with others.

Circle one:      strongly disagree      disagree      agree      strongly agree

10. I often read religious books, magazines, or pamphlets.

Circle one:      strongly disagree      disagree      agree      strongly agree

11. I often watch or listen to religious programs on television or radio.

Circle one:      strongly disagree      disagree      agree      strongly agree

12. My spiritual beliefs are the foundation of my approach to life.

Circle one:      strongly disagree      disagree      agree      strongly agree

13. I am often aware of the presence of a higher being in my life.

Circle one:      strongly disagree      disagree      agree      strongly agree

14. I have a personal relationship with a higher being.

Circle one:      strongly disagree      disagree      agree      strongly agree

15. When I am ill, I pray for healing.

Circle one:      strongly disagree      disagree      agree      strongly agree

16. I pray often.

Circle one:      strongly disagree      disagree      agree      strongly agree

17. I rely on a higher being to keep me in good health.

Circle one:      strongly disagree      disagree      agree      strongly agree



## APPENDIX J

### RACIAL PRIDE SUBSCALE

**Directions:** Please read each question and circle the answer that is closest to your opinion

18. African American/Black people make America strong.

Circle one:      strongly disagree      disagree      agree      strongly agree

19. The individuals I respect most in life are African American/Black.

Circle one:      strongly disagree      disagree      agree      strongly agree

20. Being African American/Black is an important part of who I am.

Circle one:      strongly disagree      disagree      agree      strongly agree

21. I feel a strong connection to other African American/Black people.

Circle one:      strongly disagree      disagree      agree      strongly agree

22. Racial pride is important for developing strong African American/Black families.

Circle one:      strongly disagree      disagree      agree      strongly agree

23. I think everybody should be taught about how African American/Black people helped to build America.

Circle one:      strongly disagree      disagree      agree      strongly agree

24. Black people should keep up with issues that are important to the African American/Black community.

Circle one:      strongly disagree      disagree      agree      strongly agree

## APPENDIX K

### PHYSICIAN-PATIENT COMMUNICATION SUBSCALE

**Directions:** Please rate the medical staff who takes care of your HIV needs in each of the following things.

How is the medical staff who takes care of your HIV at:

25. Explaining the results of tests in a way that you understand?

Circle one:      poor          fair          good          very good          excellent

26. Giving you facts about the benefits and risks of treatment?

Circle one:      poor          fair          good          very good          excellent

27. Telling you what to do if certain problems or symptoms occur?

Circle one:      poor          fair          good          very good          excellent

28. Demonstrating caring, compassion, and understanding?

Circle one:      poor          fair          good          very good          excellent

29. Understanding your health worries and concerns?

Circle one:      poor          fair          good          very good          excellent

30. Talking with you about your sex life?

Circle one:    n/a          poor          fair          good          very good          excellent

31. Asking you about stresses in your life that may affect your health?

Circle one:    n/a          poor          fair          good          very good          excellent

32. Asking about problems with alcohol?

Circle one:   n/a            poor            fair            good            very good            excellent

33. Asking about problems with street drugs like heroin and cocaine?

Circle one:   n/a            poor            fair            good            very good            excellent

## APPENDIX L

### SOCIODEMOGRAPHIC QUESTIONNAIRE

**Instructions:** Please check the box next to the response that best describes you in each category.

34. **What is your sex?**

☐ Male

☐ Female

35. **What is your age?** \_\_\_\_\_

36. **What is your sexual orientation?**

☐ Heterosexual or straight

☐ Bisexual

☐ Gay or lesbian

☐ Decline to answer

37. **What is your marital status?**

☐ Single

☐ In a relationship

☐ Married

☐ Widowed

☐ Divorced

38. **How do you describe yourself? (Please mark the option that best describes you, if other, please specify)**

☐ Black

☐ African American

☐ African

☐ West Indian Black

☐ Black American

☐ Other: \_\_\_\_\_

39. **What is the highest level of education completed?**

☐ Grades 1-6

☐ High School Graduate

☐ Grades 7-8

☐ Some Technical/Professional Degree

☐ Grades 9-12

☐ Some College

☐ Master's Degree

☐ College Graduate

☐ Doctoral Degree

☐ Some Graduate Level School

40. **What is your insurance status?**

☐ Uninsured

☐ Medicaid

☐ Medicare  
☐ Other: \_\_\_\_\_

☐ Private Insurance

**41. Were you born in the United States?**

☐ No.  
If no, in what country were you  
born? \_\_\_\_\_ **AND** for  
how long have you lived in the  
United States? \_\_\_\_\_

☐ Yes  
If yes, in what state:  
\_\_\_\_\_ **AND** for how long  
have you lived in Virginia?  
\_\_\_\_\_

**42. Were your parent born in the United States?**

☐ No.  
If no, in what country were your  
parents born? \_\_\_\_\_  
**AND** for how long have they lived in  
the United States? \_\_\_\_\_

☐ Yes  
If yes, in what state:  
\_\_\_\_\_ **AND** for how long  
have they lived in Virginia?  
\_\_\_\_\_

**43. Did you recently change service provider?**

☐ No

☐ Yes

**44. How long have you received services from [SITE NAME] for your HIV/AIDS?**

\_\_\_\_\_

**45. What is your current diagnosis?**

☐ HIV

☐ AIDS

**46. For how many years have you known about your HIV diagnosis?** \_\_\_\_\_

**47. For how many years have you known about your AIDS diagnosis?** \_\_\_\_\_

**48. When did you seek help for your HIV/AIDS diagnosis?**

☐ Immediately  
☐ Within 6 months

☐ Within 1 year  
☐ After 1 year

**49. Besides your medical staff, who knows about your HIV/AIDS status? (check all that apply)**

☐ No one  
☐ Mother  
☐ Father  
☐ Sister  
☐ Brother

☐ Other relatives  
☐ Friends  
☐ Pastor or other church members  
☐ Employer  
☐ Other: \_\_\_\_\_

**50. Is your physician/nurse practitioner that manages your HIV/AIDS treatment African American/Black?**

☐ No

☐ Yes

51. **Is your nurse/social worker at [SITE NAME] African American/Black?**

☐ No

☐ Yes

52. **Are the other staff (secretary, pharmacist, etc.) at [SITE NAME] African American/Black?**

☐ No

☐ Yes

53. **To what extent do you trust your physician that manages your HIV/AIDS?**

☐ I do not trust my physician at all.

physician.

☐ I do not trust my physician.

☐ I trust my physician.

☐ I neither trust nor distrust my

☐ I trust my physician very much.

54. **How do you cope with your current diagnosis?**

☐ I pray/go to church

☐ I use substance (illegal drugs, prescription drugs, alcohol, etc.)

☐ I see a counselor/psychologist

☐ I over/under eat

☐ I talk to my friends/family

☐ I am not coping

☐ Other: \_\_\_\_\_

55. **How is your coping technique working for you? (Please circle the answer that is closest to your opinion)**

Not ----- Neither ----- Working  
working well  
1 2 3 4 5 6 7 8 9 10

56. **Are you willing to see a counselor/psychologist regarding any health concerns?**

☐ No

☐ Yes

If yes, would it make a difference if the counselor was African American/Black?

☐ No

☐ Yes

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## **BIOGRAPHY**

Winifred F. Betts-Campbell graduated from Falls Church High School, Falls Church, Virginia, in 2003. She graduated cum laude with a Bachelor of Science in 2006 from Old Dominion University, with a major in psychology and a minor in human services counseling. In 2009, she received her Master of Arts in Clinical Psychology from Argosy University followed by a post-master's certificate in counseling in 2010 from George Mason University. While obtaining her doctoral degree at George Mason University, Winifred received the College of Education and Human Development's fellowship in the fall of 2012, 2013, and 2014. She has been employed as an Intellectual Disability Support Coordinator in Prince William County for over four years. Winifred has worked with geriatric patients in a nursing home, at risk youth and families in the community, volunteered as an outreach worker with Metro TeenAIDS and a volunteer HIV counselor with the Whitman-Walker Clinic in the District of Columbia. Winifred is also a mentor and member of SisterMentors, a non-profit organization located in Washington D.C. that focuses on supporting women and young girls of color in achieving academic and personal success. Winifred's research interests consist of (a) counseling minorities and at-risk youth, (b) HIV/AIDS prevention and interventions, (c) informing the Nation's youth about sexually transmitted infections (STIs), and (d) substance abuse.