Positive Living: HIV Facts on the Web for African Americans

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Clinical Psychology

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Abstract

The purpose of this study was to conduct a phase I trial to further test the content and construct validity of the Afrocentric website, Positive Living - HIV Facts on the Internet for African Americans. A sample of 17 African American adults was given a two-week period to review an Afrocentric-based website that was designed to provide information about HIV prevention and disease management. The content and construct validity was assessed in two phases. Phase I of the website’s content validity and accuracy was assessed, via expert consultants in the areas of behavioral medicine and HIV medical disease treatment. After the critiques offered by the experts were incorporated into the website’s design and content, the website was evaluated a second time to assess its ability to educate and raise awareness about HIV in the African American community. The data revealed that the knowledge of HIV prevention was significantly greater than before they used the website. The average pre-test score for the men was 41.6% (SD = 9.3) while the average pre-test score for the women was 48.4% (SD = 9.3). The average post-test scores for the women increased to 52.8% (SD = 14.8), but not as much as the average post-test score men, 60.5% (SD = 13). An overall, twenty-eight percent (28%) increase of knowledge was reported. The website proved to be a viable source of information to educate African Americans about HIV disease and prevention.
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Introduction
Overview of the Current Study

Definition of HIV
Acquired Immune Deficiency Syndrome (AIDS), which is also called human immunodeficiency virus-related disease, named for the virus (HIV) that causes the disorder (Winiarski, 1997). This disorder is a syndrome of many diseases, each resulting from an opportunistic agent or cancer cells that multiplies in humans who are immunosuppressed.

HIV/AIDS is devastating for the infected individual, as well as its overall impact on communities and society at large has been and continues to be enormous. This disease affects those population groups who are already vulnerable: children, women, the poor, the destitute, and millions of others whose life situations are further degraded by the denial of basic human rights. According to the Center for Disease Control (CDC, 2011) the HIV/AIDS epidemic is increasingly concentrated in low-income, urban communities in which people of color are often disproportionately represented. Such communities generally are faced with many other health and social issues, and limited resources, which makes it difficult for them to respond to the epidemic.

Background and Significance

African Americans have been disproportionately affected by HIV/AIDS since the beginning of the epidemic in the early 80s (Cohen, 1999). Between 1981 and 1983 African Americans made up 26% of the nation’s first 3,000 AIDS cases (Black AIDS Institute, 2008). If Black America was a country it would have the 16th largest epidemic in the world, with a greater population of HIV-infected individuals than the populations
of seven of the 15 countries that were the focus of the former administration’s, President’s Emergency Plan for AIDS Relief (Gayle and Lee, 2008). The negative impact of the HIV epidemic has dramatically worsened over the past 25 years as the rate of AIDS cases for African Americans doubled, compared to Whites between 1991 and 2006 (CDC, 2008). It is now estimated that more than 500,000 African Americans are living with HIV/AIDS, with an additional 20,000 to 30,000 new infections to this population each year (CDC, 2008).

African Americans, more than any other ethnicity, continue to shoulder the most severe burden of HIV in the United States (CDC, 2010). Although African Americans only make up 13% of the population, they accounted for the majority (51%) of people living with HIV in the United States, and 49% of the new infections by the end of 2006 (CDC, 2008). Despite the stability of current HIV infection rates, when compared to other ethnicities, African Americans account for a higher proportion of cases at all stages of HIV, from diagnosis to death. Between 2005 and 2008, the rate of HIV diagnoses for African Americans rose by 12%, reflecting the largest increase in rates of HIV diagnoses by ethnicity (CDC, 2010). The CDC (2010) also reported that currently HIV is the third leading cause of death for African Americans between the ages of 35 and 44. In 2006, almost twice as many African Americans died from AIDS compared to their White counterparts (CDC, 2006).

The HIV/AIDS epidemic has also significantly impacted particular subgroups within the African American population, particularly among young men and women. African American men made up 65% of all newly infected Blacks in 2006 (CDC, 2008). African American men who have sex with men (MSM) made up 63% of newly infected
Black men in 2006 (CDC, 2010). Sex with women make up about 22% of this population’s HIV infection (CDC, 2006).

African American women make up only 6% of California’s women population, but accounted for 35% of the newly diagnosed females in 2009 (California Department of Public Health, Office of AIDS, 2011). The rate of HIV diagnosis among Black women living in California is 14 times greater than their White counterparts (California Department of Public Health, Office of AIDS, 2011). Heterosexual contact is considered the greatest risk, accounting for 75% of HIV infection among African American women (CDC, 2006). Sex with IV drug users has been reported as the second greatest contributor (23% of HIV infection) to the current HIV epidemic among African American women. Moreover, since the beginning of the epidemic and all the years combined, young African American and Latina American women account for 75% of HIV infections reported among women between the ages of 13 to 24 (Yarbo, 2006).

The HIV infection rate among African American children reflects a similar picture. Of the 194 pediatric AIDS cases reported between July 2000 and June 2001, 163 (84%) were born to African American and Latina mothers. In 2005, African American children accounted for 65% of HIV-infected newborns (MMWR, 2006).

There are important differences associated with race, ethnicity, and gender concerning HIV transmission, prevention and treatment information, access and adherence to standard antiretroviral treatment for HIV infection. The African American community faces several challenges that contribute to greater rates of HIV infection. For example, risky sexual behavior with concurrent sexual partners, or with high risk persons contributes to higher rates of sexually transmitted diseases (STDs). Having an STD also
greatly increases the risk of becoming infected with HIV. Persons who also have an STD and HIV are at greater risk for infecting other people with HIV (CDC, 2010). In 2005, African Americans were reported to be 18 times more likely than White Americans to have gonorrhea and five times more likely to have syphilis (CDC, 2006). African American teenage girls were reported to have an STD twice the overall rate of American teens (CDC, 2008). A high prevalence of STDs was also reported among African American MSMs (CDC, 2008).

Injection drug use, the sharing of needles and having unprotected sex with IV drug users also increases the HIV infection rate. Injection drug use and HIV infection has been an ongoing driver of the epidemic, accounting for 22% of the infection rate among African American men and 23% of the infection rate among African American women. Sharing needles and trading sex for drugs are two common ways that substance abuse can lead to HIV and the transmission of other STDs, which places sexual partners and children of drug users at risk as well (CDC, 2010).

There are also many psychosocial and economic difficulties that are mediating factors in their disease progression, quality of life, and survival rate. Yarbo (2006) indicated that when dealing with HIV in the African American community there are many cultural issues that come to bare such as, stigma, denial, invisibility, classism, sexism, homophobia, anti-HIV drug phobia, misinformation, as well as fears of rejection, losing one’s independence, and loss of mental and emotional support.

Historically, African Americans have been at risk for lower socio-economic status, via poorer educational and vocational opportunities, and being at risk for poorer health through lack of access to health care (Byrd and Clayton, 2002; and Black AIDS
Institute, 2008)). The lack of access to health care economically and physically has led to lower rates of treatment compliance and higher incidences of complications due to living with HIV, such as depression, anxiety, substance abuse, premature progression to AIDS, and death (Citron, Brouillette, Beckett, 2006).

Specific Aims of HIV Treatment

There are four main goals of HIV treatment: 1) reduce HIV-associated morbidity and prolong the duration and quality of survival; 2) restore and preserve immunologic function; 3) maximize viral load suppression for as long as possible; and 4) prevent HIV transmission (Guidelines for the Use of Antiretroviral Agents in HIV-I-Infected Adults and Adolescents, Department of Health and Human Services, January, 2011).

The standard approach to HIV treatment is multidisciplinary, which involves coordinated care to address the deleterious effects of the virus throughout the patient’s lifespan. It includes monitoring the infected patient’s immune system for symptoms of opportunistic infection, via T-cell status and viral load. The treatment team may be as small as a nurse collaborating with a primary care physician to as diverse as having a physician, a pharmacist, a psychologist, a dentist, optometrist, among others, who are all knowledgeable about the medical and psychosocial implications of HIV disease management. The treatment team is usually led by a physician or a nurse who directs the patient on what course of treatment to pursue. In this traditional model of Western medicine the patient is usually passive and uninformed, at least initially.

At a cursory glance, one can appreciate the obvious limitations of such a comprehensive approach: 1) it is too expensive for the majority of patients, 2) it is too labor intensive for many community health care clinics. These treatment challenges are
particularly true for urban populations who neither have the time or resources due to the management of every-day health care demands of an urban population. Further, becoming familiar with the treatment itself is usually a daunting endeavor for the average patient. Although stepwise care informed by a multidisciplinary team specialized in HIV prevention and disease management is the optimum treatment, this level of care is often unavailable to African Americans living with HIV. Moreover, most African Americans, especially those living with HIV are not aware that such comprehensive treatment is available. If they do know, they do not know how to navigate such a complex healthcare system. Bare in mind that the estimated life time cost of treating for case of HIV in the United States is over $620,000 (Black AIDS Institute, 2008). Many African Americans living with HIV are not aware that such programs as the Ryan White Fund and Medicaid exist to financially assist them with paying for their treatment. One-fifth of African Americans do not have health insurance (Black AIDS Institute, 2008).

The pharmacological treatment for HIV is one of the most complicated aspects of managing this chronic disease. The replication of the virus is slowed with a regimen of highly active antiretroviral treatment/therapy (HAART), which are used in the appropriate combinations. HAART therapies have proven instrumental in prolonging people’s lives since their introduction in the early to mid-1990s (Bartlett and Finkbeiner, 2001). Generally known as combination therapies, HIV experts and researchers agree that HAART or ART (antiretroviral therapy) have become a widely accepted key factor in prolonging the life of people living with the HIV virus (Bartlett and Finkbeiner, 2001; Grodeck, 2003; and Bartlett, Gallant, and Pharm, 2009).
Although there has been a dramatic increase in the use of HAART to reduce the effects of HIV among all populations, African Americans have lower rates of access to treatment, (67%) compared to Whites (72%), and (79%) for Asian/Pacific Islanders (CDC, 2006). The same CDC report also found that African Americans continue to lag behind other populations in survival rates. For example, African Americans living with HIV have an estimated survival rate of about 3 years after diagnosis, a significantly lower rate of (79%) when compared to Whites (86%) and Latinos (87%) (CDC, 2006). Nearly 40% of African Americans diagnosed with HIV in 2005 were diagnosed with AIDS about one year later (Black AIDS Institute, 2008). Almost 70% of newly diagnosed African Americans in Washington, D.C. were given an AIDS diagnosis within the following year. (New York City Department of Health and Mental Hygiene, 2007; and District of Columbia Department of Health, 2007). In New York City, this survival is drastically reduced. About 26% of African American New Yorkers diagnosed with HIV received an AIDS diagnosis one month later.

HAART is the treatment of choice due to its effect of reducing the amount of HIV to undetectable levels in the bloodstream, decreasing the risk of opportunistic infections, resulting in the patient feeling better, experiencing improved quality of health, and living longer (Brett and Grodeck, 2003; Bartlett, Gallant, and Pharm, 2009). HAART medications were formerly taken in the form of a “cocktail” with as many as 30 pills a day, depending on the regimen (Stine, 2000). However, these medications have been re-formulated, combining 3 pills into one, which are administered once or twice a day (Bartlett and Gallant, 2007). Despite these advances in treatment, antiretroviral medications continue to be difficult to take because they still produce significant side
effects such as, headache, nausea and diarrhea (Bartlett and Finkbeiner, 2001; and Bartlett, Gallant, and Pharm, 2009). Outdated reputations of toxic side effects from older regimens also continue to deter uninformed patients from seeking life saving treatment.

Schrub (1997) described three factors that are very important to successful combination therapy of HIV: compliance, absorption, and resistance. Problems with treatment adherence are common due to the complex issues associated with life-long pill taking and the prohibitive consequences of the side effects. Although the complexity of the medication regimen has been simplified with the development of newer drugs, which have less pills to take and less food restrictions, the risk of short and long term side effects continue to contribute to poor adherence (Kane, 2008). Nearly one-third (31%) of newly diagnosed people with HIV are linked to outpatient HIV medical care within six months of testing positive, but only 59% stay in care over time (Mugavero, 2011).

Although the pharmacological industry has made many advances for HIV treatment, there continue to be very real risks regarding side effects that contribute to poor adherence. For example, the Nucleoside Analog Reverse Transcriptase Inhibitor (NRTIs), Epzicom is usually well-tolerated (Gallant, 2011). However, because it is made from the combination of two drugs (Ziagen and Lamivudine), the Ziagen component carries a risk of hypersensitivity reaction (HSR). Although this risk is rare, it can be fatal. All drugs within the NRTI class also have common side effects of nausea, upset stomach, diarrhea, fatigue, headache, loss of appetite, to more serious, such as increased risk of heart attack, liver toxicity, potential lactic acidosis and liver failure (Gallant, 2011). When HIV patients have an extensive regimen of other medications medication for co-occurring illnesses like diabetes or hepatitis C, compliance is further complicated
(Bartlett, Gallant, and Pharm, 2009). As a result, patients taking these antiretroviral medications who experience these side effects are often noncompliant with treatment. Some studies have reported noncompliance rates as high as 80 percent (Kane, 2008). However, adjunctive treatment adherence support has been shown to have a positive impact on this treatment problem (Levensky and O’Donohue, 2006).

To further complicate HIV treatment issues regarding access and medication adherence, HIV patients suffer from psychosocial difficulties of stigma, depression, anxiety, isolation, and physical, as well as, neurological debilitation (Citron, Brouillette, and Beckett, 2006). These treatment issues cannot be overstated because they compromise immune functioning, increase disease progression, reduce necessary health care utilization for preventative treatment of opportunistic infections, and other HIV/AIDS-related, preventable illnesses (Citron, Brouillette, and Beckett, 2006). Evidence suggests that these problems occur at higher rates among African Americans since this population has historically been at risk for lower socio-economic status, via poorer educational and vocational opportunities, and being at risk for poorer health through lack of access to health care (Byrd and Clayton, 2000). The lack of access to health care due to poverty and lack of transportation has also contributed to lower rates of treatment compliance and higher rates of HIV-related complications, such as opportunistic infections, depression, anxiety, and substance abuse (Aronstein, and Thompson, 1998; and Levenson, 2004). In New York City, African Americans make up 62% of the HIV-infected homeless population (Black AIDS Institute, 2008).

Although the majority of African Americans living with HIV are in urban settings, many live in places that are poorly served by mental health and health care
services (Levenson, 2004). The services that are available are often under-staffed, expensive or difficult to access. A 1991 national study found that the majority of American hospitals in rural areas were only equipped to provide acute-care services for HIV patients (Fuszard, Sowell, Hoff, and Water, 1991). Although they were knowledgeable about universal precautions, community services and many other patient care services were unavailable.

The number of HIV/AIDS cases in some southern rural areas has increased. For example, African Americans made up 34% of the AIDS cases in Tennessee (Levenson, 2004), 69% of Alabama’s new HIV/AIDS cases in 2006, 70% of Georgia’s HIV population, and 80% of Jackson, Mississippi’s AIDS population (Black AIDS Institute, 2008). Dramatic increases were also reported in Kentucky (59%), and North Carolina (41%) (Yarbo, 2006). Additional treatment barriers can be geographic – the broad spread of cases over a large area, lack of services, homophobia (Levenson, 2004), and hostility from official authorities towards evidence-based HIV prevention strategies such as, needle exchange programs (Black AIDS Institute, 2008).

**Treatment Barriers for African Americans**

HIV prevention and treatment is not that simple in the African American community. Institutional racism in health care has also significantly affected not only access to health care for African Americans, but also the quality of health care received, access to hospitals and health care institutions, access to culturally competent medical staff, employment, and health insurance (Randall, 2002). U.S. health indicators suggest that, in general, the health of racialized minorities is poorer than that of the population in general (Mmaje, 2000). For example, infant mortality rates among African Americans are
nearly double that of Whites, and overall, mortality rates for African Americans are higher for all ages, except in the very oldest groups (Shapiro, 2004). A particular feature of concern is that life expectancy for African Americans has decreased in absolute terms since the late 1980s. In 1999, the U.S. Commission on Civil Rights reported to the President and the Congress that the government’s failure to recognize and eliminate racial differences in health care delivery, financing, and research presents a discriminatory barrier that creates and perpetuates differences in health status (Randall, 2002; and Shapiro, 2004).

Dalton (1991) described five overlapping factors that continue to impede the response of Black communities to the AIDS pandemic:

1. Stigma related to the reluctance to address HIV/AIDS crisis as a central health care issue;

2. The Tuskegee Effect;

3. Stigma of homosexuality;

4. Mental health concerns; and

5. Western medicine’s lack of cultural sensitivity.

The first factor is the reluctance to acknowledge association with AIDS due to mainstream attempts to blame people of African descent as the race responsible for its origin and initial spread. Cohen (1999) attributed much of African Americans’ lack of appreciation for their own risk of contracting HIV to the poor presentation by the media.
regarding HIV’s prevalence among the Black community. She described how the media’s excessive focus on White gay men and IV drug users, as well as the lack of governmental policy concerning epidemiology and prevention has lead to pandemic HIV among African Americans. As a result, she argued, there has been detachment and separation between the AIDS epidemic and the African American community (Cohen, 1999).

The stigma of HIV/AIDS in the African American community continues to be a very real barrier to being tested and accessing treatment (Stutterheim, Pryor, Bos, Hoogendijk, Muris, and Schaalma, 2009). The literature defines HIV/AIDS-related stigma and discrimination as prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS. These effects can result in being shunned by family members, peers and the wider community; poor treatment in healthcare and education settings; an erosion of rights; psychological damage; and can negatively affect the success of HIV testing, access to care, and treatment (UNAIDS, 2003; Dodds, Keogh, Chim, Haruperi, Nabulya, Sseruma, Weatherbum, 2005; and Ogden and Nyblade, 2005).

There are two additional aspects of the HIV within this community that contributes to stigma: being associated with death as having or transmitting a fatal disease, and the view that it is transmitted by already stigmatized groups, such as gay men (particularly Black men who have sex with men on the down low) and IV drug users. HIV has increasingly become associated with marginalized groups, such as poor people of color, particularly African Americans (CDC, 2011). Stigma often leads to discrimination, isolation, and indifference toward those affected (Hoffman, 1996). Stutterheim, et. al. (2009) reported that persons living with HIV who experience high
levels of stigma are more than four times more likely to report poor access to care and treatment. This has had real consequences regarding increased infection rate among the Black community because it leaves people afraid to be tested and to seek treatment. As a result, less people don’t get treated until they are very sick, which makes them more infectious and at greater risk of unwittingly passing the virus to their partner, via unprotected sex.

Stigma about HIV disease has been an ongoing problem. A survey conducted by the Henry J. Kaiser Foundation in 2001 reported the following findings: 87% of African Americans say that prejudice and discrimination against people living with HIV/AIDS exist in the U.S. today with similar proportions of Latino (85%) and White (84%) in agreement; African American and Latinos are significantly more likely than Whites to believe that “a lot” of discrimination exists (65% vs. 57% and 49%, respectively); two-thirds (67%) of African Americans believe that such discrimination has either stayed the same or improved in the past five years while 29% reported it to have gotten worse; and 81% of African Americans reported that access to HIV care and treatment in the U.S. is a problem, with the majority saying that access is affected by income, race, and gender (83%, 70%, and 49%, respectively). More recently, a greater percentage of African Americans, more than any other racial group, believed there continues to be ‘a lot’ of prejudice and discrimination against people living with HIV and AIDS in America (Moutsiaakis and Chin, 2007).

Stigma about HIV disease itself, and towards HIV+ people are believed to be based on misconceptions about the virus. The Kaiser Family Foundation (2006)
consistently reported significant levels of misinformation among African Americans regarding HIV transmission. They found the following: 38% of African Americans sample believed that HIV can be transmitted by kissing compared to 33% and 26% for Latinos and Whites, respectively; sharing a drinking glass - 25% of African Americans compared to 17% of Latinos, and 15% of Whites; sitting on a toilet seat - 13% of African Americans compared to 14% for Latinos, and 8% of Whites. The findings of this study suggest that misinformation about HIV may be at the center of HIV-related stigma and misconceptions, placing African Americans at greater risk. This research was also supported by the earlier findings of Levenson (2004) who described the HIV-related stigma associated with the HIV diagnosis itself. Among the rural, African American communities of the southern United States, the fear of being labeled HIV+ was the main treatment barrier, regardless of gender and sexual orientation. One of the main purposes of this website project is to provide psychoeducational information that may serve to dispel contemporary myths and misperceptions about HIV transmission, prevention, and treatment.

A recent survey conducted to assess HIV-related stigma among African American doctors found that only one-third of their patients had been tested within the last year (Jordan, W., Stone, V., DeLaitsch, L., et al., 2011). Although 93% of this sample of doctors believed that HIV is a very serious crisis in the African American community, stigma continues to be a significant barrier to recommending routine testing of their patients. Jordan, Stone, DeLaitsch, L., et al. (2011) reported the following top five barriers regarding HIV-related stigma with African American doctors: 57% were
concerned about being perceived as accusatory or judgmental of their patients; 48% did not want to be identified as HIV positive and were worried that people would find out; 43% felt that their patients would be offended; competing priorities 45%; and not enough time to address it 45%. These are discouraging findings considering these are the Black community’s frontline medical providers for fighting HIV, particularly when most patients decide to get tested based on a recommendation from their doctor. The researchers also reported that physicians surveyed were still using the out-dated risk-based testing approach (Jordan, Stone, DeLaitsch, L., et al., 2011). This is also a concern for following best practices of medical care. As of September, 2006, the CDC has recommended that diagnostic HIV testing and optional HIV screening be part of routine clinical care in all healthcare settings (CDC, 2006). A function of the website could be to educate all African Americans about appropriate HIV prevention recommendations, such as learning to ask their medical providers for an HIV test.

No single issue about HIV is more controversial and provokes more hostility in the African American community than the HIV-related stigma concerning the origin of the HIV virus being blamed on people of African descent. Although several theories have emerged from White researchers, the one that engenders the most hostile response from the Black community is the commonly purported theory is that HIV began in Africa, via an African monkey that transmitted the virus to Africans (Essex & Kanki, 1988). Some White researchers have even suggested that Africans caught the virus by drinking monkey blood and/or through sexual intercourse with monkeys. These theories are vehemently rejected by the African American scientific community and dismissed as
racist interpretations of available scientific data (Greaves, 1994). African Americans view theories of HIV origin that point to Africa as just another excuse to blame them for this disease. Moreover, these theories detract from the credibility of life-saving research and treatment offered by the mainstream scientific community. As a counter, African American researchers have responded with their own theories.

An example of such a theory is that HIV is a man-made virus that was created by the U.S. government. This theory is endorsed by a significant portion of the Black community (27%) and has been shown to be a contributing factor in the reduction of consistent condom use and medication adherence among African American men (Bogart and Thorburn, 2005). These researchers also reported that 53% of their sample of African Americans agreed that “there is a cure for AIDS, but it is being withheld from the poor”, and that 15% believe that AIDS is a form of genocide against African Americans (Bogart and Thorburn, 2005). Although further exploration of this issue further is beyond the scope of this research project, when viewed in the context of other U.S. government experiments conducted upon African Americans (e.g. the Tuskegee Syphilis experiment), the skepticism among the Black community regarding the origin of HIV appears to be appropriate and valid. However, this skepticism has been found to be harmful when these beliefs extend as far as reduced prevention and medication adherence rates of 68%, which are too low to prevent virological failure and the development of drug-resistant strains (Bogart, Wagner, Galvan, and Banks, 2010).

2. The second factor relates to the “Tuskegee Effect”, which refers to the African American community’s historical mistrust of Western approaches to medicine (Johnson,
much of the mistrust is related to the infamous 40-year government-funded Tuskegee Syphilis Study that was sanctioned by the U.S. Public Health Service from 1932 to 1972, in which 399 African American men in Alabama were intentionally allowed to languish and die due to untreated syphilis.

The Tuskegee Syphilis Experiment helped to establish the foundation for Blacks’ pervasive sense of mistrust of public health authorities today. As a result, fears of genocide have been reported by public health professionals and staff who work in Black communities (Thomas and Quinn, 1991). Nearly two decades later, Hammond, Matthews, Mohottige, Agyman, and Corbie-Smith (2010) examined the medical mistrust and treatment seeking behaviors among African American men. Hammond, et. al (2010) reported that African American men who were found to be highly mistrustful of the medical system were more than twice as likely to delay routine checks-ups (e.g., cholesterol screenings), and three times likely to delay having their blood pressure checked by a doctor or health care professional than men who were less mistrustful.

The mistrust of African Americans continues to be validated in the health care disparity and minority health outcome literature. In 1994, researchers reported that 63% of eligible Whites vs. 48% of eligible Blacks received antiretroviral therapy (Moore, Stanton, Gapalan, and Chaisson, 1994). Moore, et. al (1994) found that only 58% of eligible Blacks received prophylactic therapy vs. 82% of eligible Whites. The New York Times reported in 1997 that doctors were rationing protease inhibitors and other new antiretroviral because they were “saving them for patients they believed were more likely
to comply” (Pear, 1997). Research examining racial differences in medical treatment found that Black Medicaid beneficiaries were given less intensive medical procedures and treatment than White patients concerning diabetes (Kehoe, 1999). African Americans were more likely to undergo amputation of the leg or foot and less likely to undergo limb-saving, lower-extremity arterial revascularization surgery. This is a concern because two thirds of African Americans rely on publicly funded programs such as Medicaid to pay for their treatment (Kaiser Family Foundation, 2006).

The above findings are particularly troubling, considering that physicians are poor predictors of which patients will comply with prescribed regimens (Sumartojo, 1993). Moreover, it’s not that patients are willfully noncompliant, it’s that those least likely to comply are usually the poorer patients who are least able to comply (Farmer, 2003). Dr. Paul Farmer argued that many of the day-to-day challenges of poverty, racism, unemployment, addiction, lack of health insurance, lack of stable housing are just a few of the many obstacles that many HIV positive people of color face. He emphasized that rationing effective therapies serves to worsen the class-based gaps between the rich and the poor over time. Dr. Farmer framed the argument of unequal treatment regarding poor people living with HIV as an ethical dilemma faced by modern medicine in his famous book, “Pathologies of Power: Health, Human Rights, and the New War on the Poor”. He stated that when market forces are allowed to determine who has access to new drugs, the majority of the world’s HIV+, who are also the world’s poorest, living on less than $2 a day, are written off due to their inability to afford treatment (Farmer, 2003).

The glaring disparity of millions of Africans being denied antiretroviral treatment in the interest of profit is likely to have negative treatment implications for seropositive
African Americans who are having difficulty trusting the treatment offered in the U.S. health care system, one of the world’s biggest supporters of large pharmaceutical companies. Nessel and Primm (2004) suggested that such levels of distrust may have an impact on the general willingness of African Americans to be tested for HIV or to listen to a physician’s advice about adhering to HIV-related treatments. A 2002, IOM study suggested that the mistrust described in the studies regarding the belief of HIV conspiracy theories among African American are more reactions to the biased manner in which they are treated by clinicians who have negative expectations of African American patients.

Racial disparities in medical treatment exist, particularly for women of color who have mostly been ignored by the health care system (Randall, 2002). Laurence and Weinhouse (1994) devoted a chapter in their book, “Outrageous Practices: The Alarming Truth About How Medicine Mistreats Women”, to address the invisibility of women with AIDS as a result of institutionalized sexism and racism. They attributed the unequal treatment of women to the flawed medical model, which revolves around the treatment of the 155 pound, middle-class, gay, Caucasian male. As a result, a greater percentage of low-income African American and Latina American women who have HIV/AIDS receive inadequate medical services. Lekas, Siegel and Schrimshaw (2006) found that the challenges of experienced stigma for women continue to exist, despite the advances of HAART.

Although the discovery of the Tuskegee Experiment occurred almost four decades ago, residuals of it’s unethical legacy still occur. Talvi (2002) described the prevalence of research on prisoners as being “on the rise”. Talvi indicated that with high numbers of
people being incarcerated, researchers are eager to test experimental procedures for a variety of medical problems such as, cancer, asthma, including experimental vaccines for HIV. Experiments that were conducted involved inmates signing waivers, giving up their right to future compensation if they were harmed from side effects (Talvi, 2002). In December, 2004, the UK Observer published an article, which exposed the abuses of American, HIV+ orphan children (mostly African American and Latino) that were subjected to approximately 35 experiments conducted by the GlaxoSmithKline pharmaceutical company. The experiments, many of them phase I (the most dangerous) were done on infants as young as 6 months old to test the toxicity of anti-bacterial drugs, Herpes drugs, and the tolerance of HIV drugs such as AZT, which has dangerous side effects (Barnett, 2004). An August 29th, 2011, Washington Post article exposed the unethical STD research conducted in Guatemala by the U.S. Public Health Services between 1942 to 1946 (Stein, 2011). The news of the heinous research conducted on thousands of Guatemalans who were infected with venereal diseases likely serves as a cruel reminder of the similar Tuskegee study to which African Americans were subjected.

The Tuskegee Effect may also have a negative impact concerning the lack of African American participation in clinical research. Gifford (2002) found that African Americans and Latino Americans are only half as likely as Whites to participate in clinical trials of new antiretroviral medications. Gifford also reported that the African American and Latino patients’ limited attempts to obtain experimental HIV medications may not only reflect suspicion and distrust of clinical trials and researchers. Gifford attributed their lack of participation to not knowing about the availability of clinical trials.
Moutsiakis and Chin (2007) also found similar mistrust and suspicions among their sample, which they attributed to misinformation as one of the main factors that limits African Americans from participating in clinical trials. They also noted that African Americans continue to be misinformed that HIV is still a gay, White disease despite the fact that the majority of new infections (20,000 - 30,000) each year are among African Americans (Moutsiakis and Chin, 2007).

Thus, any culturally sensitive prevention and treatment designed to serve the African American community must address the issue of mistrust of the Western-oriented health care system, as well as employing empowering strategies to assist with navigating an inherently biased system. This research affords that opportunity to educate African Americans concerning misinformation that may be a barrier to getting tested and getting treated. This dissertation research also offers an effective way to address the issue of mistrust as a treatment barrier by offering such useful tips as finding an HIV doctor, maximizing your doctor’s visit and how to manage side effects.

Another challenge regarding treatment adherence among HIV+ African Americans is the issue of medication noncompliant related to side effects. Bogart, et. al. (2010) reported that poor adherence was partially due to the mistaken belief that the experience of side effects was an indicator that the medication are harmful, or deadly, instead of normal and temporary. In the average 8 minute doctor’s visit primary care providers do not have time to explain the important aspects of potential side effects and their effective management. An important feature of the website could be psychoeducational such as, informing this population about HIV disease and treatment by explaining when to start antiretroviral medications, what to expect when taking an
antiretroviral regimen. For example, the website explains treatment guidelines and that side-effects are normal and usually temporary until your body adjusts to the medication (Grodeck, 2003).

Another feature of the website would be to address the Black community’s mistrust by using African American experts and scholars to inform the website. Their expertise and input can be used to explain complicated aspects of HIV disease in linguistically sensitive terms that are easy to understand. These experts have demonstrated credibility, through years of dedicated professional work, via sincere assistance to African Americans living with HIV. As a future African American clinical psychologist concerned with the psychological and physical health of the African American community, developing a website that is informed by African American expert doctors, medical practitioners, and scholars offers an added feature of reducing medical mistrust and providing credible HIV information in a web-based format for this underserved population. This will ensure the delivery of culturally relevant, empirically supported disease management techniques and information unique to this population such as, harm reduction strategies, safe sex practices, and psychosocial support strategies to address such HIV disease management issues such as, social isolation, anxiety, and depression.

An additional feature of the website is that it explains complicated HIV disease terminology and process in easily understood terminology that is linguistically sensitive to this group. Researchers have known for some time that African Americans living with HIV, who have lower rates of literacy are also at greatest risk of lower rates of accessing treatment and treatment adherence (Kalichman, Catz, and Ramachandran, 1999). Having
access to free HIV information, this research offers a unique opportunity to explore viable ways of improving the health literacy of this subset within the African American community.

3. Homophobia is the third important factor. The issue of homosexuality in the African American community is highly stigmatized and very complex. Like most communities of color it has been shrouded in secrecy and too taboo for open discussion. Major cultural institutions, such as the Black church, have actively disapproved of this sexual orientation, and described it as “living outside of God’s law, as a sin, as punishment for not living right” (Foster, 2007). Therefore, the experience of being gay in the African American community is often filled with the difficulties associated with stigma, shame, and secrecy.

In the Black community, homosexuality is not only viewed as individual sexual preference with stigma as in the European American community. It is viewed as a threat to the survival of the Black family (Hare & Hare, 1993). It is also viewed by some African American scholars as the result of continued manifestation of institutional racism and oppression against the African American family, particularly African American men (Afrika, 1998; and Welsing, 1991). Such scholars view African American maleness, responsibility, well-being, and manhood as consistently under attack and disrupted by slavery, lynchings, sexual rape, police brutality, high unemployment, high rates of incarceration, assimilation and dehumanizing media images. Brutal assaults on and murders of African American men continue (e.g. the 1997 murder of Ennis Cosby – murdered by a young White male who bragged, “I just shot a nigger and it’s all over the news”; the 1998 murder of James Byrd, Jr. – who was chained up and dragged to his
death by four White men; the 2009, shooting death of Oscar Grant on an Oakland subway platform by a White Bay Area Rapid Transit (BART) police officer; the murder of Trevon Martin in 2012 by George Zimmerman, as well as many less-known others). Similar to the Rodney King incident, Oscar Grant’s murder was videotaped and posted on the Internet, which sparked outrage throughout Black America. Despite evidence of his unarmed murder the BART officer only received 2.5 years for this murder. Most recently, George Zimmerman was acquitted of Trevon’s murder by an all-White jury. Mindful of the tragic history and contemporary horrors that African American men endure, many in the African American community are further disconcerted when their men reveal themselves as homosexual or transgendered (Manago, 1998).

Dr. Francis Cress-Welsing (1991) contends that there is an unspoken self-consciousness and humiliation about the disruption of Black males lives and manhood in the African American community under the system of White supremacy. She suggested that many African Americans see homosexuality (particularly among males) as a disturbing by-product of the circumstances perpetuating the demise of African American men, families and community. Dr. Welsing (1991) describes homosexuality as a major tool of White supremacy because it perpetuates Black male passivity through encouraging feminization, bisexuality, and homosexuality. Dr. Welsing contends that this is a problem of epidemic proportions among Black people in the U.S. She also suggested that homosexual patterns of behavior are simply expressions of African American male self-submission to European American males in the domain of “sex”, as well as in other areas – economics, education, entertainment, labor, law, politics, religion, and war. As
oppression is defined as forced submission, homosexuality is viewed as a sign of weakness (Cress-Welsing, 1991).

Many scholars among the Black consciousness and/or Afrocentric movements are hyper-sensitive about introductions of European/White ideas into the Black community and homosexuality is seen as just that. An avid supporter of such an opinion is Dr. Afrika, (1998), who believes that homosexuality is a degenerative state and a disease resulting from sexual addiction, White supremacy, diet, and institutionalized subliminal recruitment techniques. He also believes that homosexuality was introduced to Africa and African Americans as European invasions on African and African American life and culture. Hare & Hare (1993) suggest that homosexuality is a product of Europeanized society that is a means of population control because it does not promote African American family stability. They proposed a policy of compassion and acceptance without advocacy of homosexuality while openly opposing sources of African American confusion regarding sexual orientation.

The resulting stigma of homosexuality has resulted in gay African American men to disassociate themselves with being gay, in an effort to avoid stigma and blame for the current rise in HIV infection rate in the Black community. Although she found very little evidence to support these latter claims, Ford (2007) suggested that Black men who have sex with men and identify as being on the down low, have been unable to benefit from effective prevention strategies designed for openly gay White men or straight Black men. Qualitative research conducted in the U.S. have found that Black gay and Black Men Who Have Sex with Men (MSMs) perceive significant stigma in their families,
communities and churches, which reduces their willingness to disclose their homosexual status, or to seek social and/or spiritual support (Black AIDS Institute, 2008). These authors also suggested that Black MSMs may experience social pressure to conform to heterosexual norms, resulting in their seeking female partners, which increases physical and emotional risks to women. The current phase of this web-based research project can be to present up-to-date statistics for Black MSMs as rationale for safe sex practices (e.g. consistent condom use). A later extension of this research project could be to provide web-based links to resources for Black MSMs of places in their community to go for medical, social and spiritual support.

4. The fourth barrier is the contentious relationship that most African American communities have regarding mental health and substance abuse. Although a discussion of substance abuse is beyond the scope of this dissertation, it is the intention of future research to address this issue among African Americans living with HIV/AIDS. Studies have shown that people living with HIV/AIDS who also have co-occurring mental health and addictive disorders are at high risk for poor health outcomes (Blank and Eisenberg, 2007).

Substance use and abuse, particularly injected drugs, has also been seen as a major contributing factor of high rates of HIV/AIDS among African Americans. Women IDUs were found to be less compliant than men in taking the medications, and rates of hospitalization were higher among women than men (Finnegan, Sanders-Phillips, and Schoenbaum, 2001). Studies have reported as high as 40% IV drug use among urban African Americans with HIV (Fullilove, 2006; and Stockman, Strathdee, 2010). The
estimated epidemiology of HIV and drug use and mental illness are as follows (NIDA, 2011):

- About 25% abused alcohol;
- More than half of new HIV infections per year in the U.S. are from IV drug use either by directly sharing a needle, or by unprotected sex with an IV drug user;
- Between 50% to 70% of HIV+ people smoke cigarettes;
- As high as 80% of HIV+ people experience depression at some point in their illness;
- Another 30% met criteria for anxiety disorders; and
- More than 25% met criteria for panic disorders (PTSD).

Depression has been called the world’s number one health problem, the “common cold of psychiatric illnesses” (Burns, 1980). Approximately 80% of people living with HIV will experience depression at some point in their illness (Blank and Eisenberg, 2007). Gorman et al. (1991) indicated that HIV+ persons with the greatest degree of medical complications were also most likely to be depressed and anxious. Lykos et al. (1996) investigated the course of depressive symptoms among HIV+ persons. They found that two to five years before the onset of AIDS, depressive symptoms were stable. At about 18 months before the diagnosis of AIDS, there was a significant increase in all measures of depression, which reached a fairly stable level of for the last six months prior to full-blown AIDS.

Ciesla and Roberts (2001) conducted a meta-analysis of 10 studies between 1988 and 1998. They found that HIV-positive individuals are nearly two times more likely to have had a recent episode of major depressive disorder than HIV- negative individuals.
Despite many advances in treatment, clinical depression continues to be fairly common among people living with HIV, about 30%, making depression the most common psychiatric disorder for this population (Grodeck, 2003). Depression can affect the person’s neurological functioning, mood, immune system, and behavior (Citron, Brouillette, and Beckett, 2005).

Studies have shown that African Americans exhibit higher numbers of depressive symptoms, but lower rates of diagnosed cases and appropriate treatment (Hastings, 2001). Although as many as one in three persons with HIV/AIDS suffer from depression, reliable assessment has yet to be conducted on the prevalence rate and affective treatments for depressed, HIV+ African Americans. This dissertation of developing a website presents a unique opportunity to inform this population about the impact of depression on HIV, it’s symptom presentation, as well as effective ways to alleviate them, if necessary.

5. The fifth factor is that African American communities still have a deep resentment for having solutions historically imposed by the construction of preventive strategies without community input. Dalton (1991) suggests that Western medicine care is underutilized by people of color because when they interact with Western health care systems, their cultural values related to health, illness, and help seeking are often at variance with the values of the dominant system. Thus, it is important to explore and develop alternative, relevant models that inform African Americans about HIV/AIDS.

Other factors that may contribute to the lack of treatment in African American communities are poverty, poor education, widespread denial, hopelessness, and religious
conservatism are a few of the reasons why African Americans are not protecting themselves when they know how to (Johnson, 2000). A host of research has consistently reported disproportionately high incarceration rates of African Americans, particularly among the men, as contributing to the high infection rates in the Black community (Alexander, 2010; and Collins, 2004).

Close examination of most current health care statistics, hospital reviews, and reviews of provider training programs clearly indicate that African Americans are not faring well in the current U.S. health care system (Black AIDS Institute, 2008; Collins, 2004; and Byrd and Clayton, 2000). The underpinnings for this current situation have deep historical roots. That contemporary health and mental health care models do not seem amenable to embracing the presenting needs of this population is no accident. Popular media and medical science have portrayed African Americans, particularly men in such unflattering ways as, buffoon, sexually promiscuous, and criminal (Alexander, 2010; Collins, 2004; Entman and Rojecki, 2000; and Wilson, 1990). Instead of promoting understanding and compassion, these negative stereotypes have done much to damage already tenuous relationships between African Americans and health care providers. The absence of African American providers, particularly men, in many health care settings provides the space for others to perpetuate stereotypes about this population that result in negative self-fulfilling experiences when services are pursued. One result has been the underutilization of health care, particularly mental health services in proactive and preventive capacities.
One example has been shown regarding the difficulty of getting African Americans, particularly men, into conventional professional counseling, let alone extended psychotherapeutic intervention, is legendary within the professional community (Franklin, 1999). African American males’ resistance to counseling is related to intrinsic gender and racial barriers, which impede usage of counseling and psychotherapy as personal resources. Once in counseling, many African American men believe that they cannot be helped, absent an appreciation of what it means to be an African American man in this society.

Research indicates that the present Eurocentric approach to psychological and medical treatment may also be an obstacle for African American men (Parham, White, and Ajamu, 1999; and Kambon, 1998). Mental health services using the one-hour-per-week format to explore problems, and rapid change, may not be the most appropriate model, given the suspiciousness of African American patients of the therapeutic milieu (Wheeler and Miller, 1999). Based upon this evidence, it is reasonable to suggest that the majority of contemporary American mental health and health service models are not constructed and have not been shown to be useful for African Americans overall. However, when therapeutic services match the sociocultural, political, and spiritual realities of African Americans the likelihood of productive outcomes are increased (Wheeler and Miller, 1999). A viable alternative would be to provide adjunctive psychosocial support through psychoeducational and psychotherapeutic techniques that have been adjusted to serve this population. However, this approach has unique
challenges, as well as demonstrated by the literature, being filled with ineffective attempts of culturally sensitive psychotherapeutic assistance.

An example is the practice of technology transfer – the transferring of a successful design and/or model from population to population without considering the specificity with which they were or were not designed. Interventions designed by and for gay White men are premised on a very specific social and cultural commonality of Whiteness. In other words, many services and programs that have been developed for White patients are transferred across populations with the assumption that they are racially neutral and that distinctions based on class, gender, and race are viewed as outside the norm (Wheeler and Miller, 1999).

Then the challenge becomes one of modifying or “Blackening” successful White programs to meet the needs of African Americans despite their heterogeneity. The treatment of the African American community as essentially one community continues to have dire consequences. As a result, some African Americans have felt repelled by, instead of feeling invited to participate in programs because of cultural insensitivity, a perceived lack of authenticity, or that undefinable quality of “realness” that is so important in contemporary African American popular culture. Further evidence of such ineffectiveness has been the steady increase in the HIV infection rate among African Americans since the onset of the epidemic (Black AIDS Institute, 2008; and Cohen, 1999). Fairly stable to increases of AIDS case diagnoses for African American men and women vs. dramatic decreases for European American men is further evidence of the ineffectiveness of the practice of technology transfers and to the need for providers to understand and develop alternative paradigms of treatment for this most negatively
impacted population. This is a difficult task, considering the need to negotiate the specificities of subgroups within diverse African American populations.

Moreover, despite the demand for support groups and/or psychological counseling for African Americans living with HIV, there has been a dearth of outcome research concerning psychological interventions that have been tailored or otherwise, developed for this population. As pandemic HIV/AIDS has shifted to disproportionately represent mostly poor, inner-city, African Americans, it has become imperative to develop and assess culturally relevant psychoeducational and intervention strategies that are cost effective and easily accessible (Kalb and Murr, 2006). Previous research has mostly focused on the following domains and intervention, which have lead to increased immune functioning, and improved quality of life for HIV+ European Americans (Hoffman, 1996). These domains have been:

- Cognitive Behavioral Stress Management (CBSM);
- Cognitive Behavioral Therapy (CBT);
- Behavioral Activation Therapy for Depression;
- Stress Management;
- Medication Adherence;
- Relaxation Training;
- Aerobic Exercise;
- Coping Effectiveness Training (CET);
- Psychoeducational information about HIV disease;
- AIDS-related Bereavement Counseling (no outcome data); and
- Exploration of Spirituality and Religious needs (no outcome data).
Although these components may have potential in effective treatment of assisting African Americans living with HIV/AIDS, their efficacy has yet to be scientifically tested. This dissertation presents a unique opportunity to begin to close the gap on this lack of information regarding African Americans’ prevention and psychoeducational HIV/AIDS treatment needs using a web-based format. Despite the lack of available data concerning what psychological interventions are most effective for African Americans, the literature contains suggestions from contemporary authors in this area of research as guidance to develop an effective psychoeducational prevention and treatment model.

Boyd-Franklin (1989) suggested that the exploration of spirituality and religious needs must be incorporated into the therapeutic process because the church may provide support, a sense of guidance, plus an adaptive mechanism for coping with stress, expressing anger, and suppressed emotion. Due to the overall reluctance of the Black church to address the concerns of their constituency living with HIV/AIDS (Cose, 2006), the modification of Boyd-Franklin’s model is a logical future research consideration.

Wilson and Stith (1991) encourage a systemic theoretical orientation to concrete problem-solving approaches in coping, via effective training techniques. Using cultural strengths such as affirming spirituality as a way to emphasize the strengthening of family ties and friends has also been found helpful for African Americans living with the HIV virus. Promoting a positive self-image and building on pride in cultural heritage to enable patients to feel more connected to their community has also been suggested to be health promoting (Tolliver, et al., 1998). They also suggested assisting clients in identifying the larger African American community as a resource that can further support their efforts to
maintain and improve their health and cope with other relevant life issues. The networking mechanisms of web links will offer this service by providing local links in the construction of the website. A live chat room, regional and national links will be a future research endeavor.

Another example of an effective intervention was a public service campaign supported by a website that was implemented in Canada to prevent the spread of HIV infection among Black Canadians (DA Faloner & Associates, 2006). Sponsored by the African and Caribbean Council on HIV/AIDS in Ontario, this prevention program used messages of HIV/AIDS awareness and how to protect one’s self from HIV transmission through positive imagery of Canadians of African descent with slogans such as, “Self Respect” and “Pride. Keep it alive.” On the bottom of each poster and postcard is the preventAIDS.ca website, which reads, “Use a condom. Get tested. Spread the word.” Although this effort was not rigorously examined, anecdotally, it appeared to be well-received by the African Canadian community of Toronto.

A similar strategy was conducted in the U.S. during the summer of 2005. Black Entertainment Television (BET) partnered with the Kaiser Family Foundation encouraging teens to “Rap it Up” and get tested (Kalb and Murr, 2006). Although BET donated $13 million in airtime, this noble gesture lacks credibility among it’s Black constituents for three reasons: 1) it was never evaluated for effectiveness; 2) BET continues to bombard young audiences with a non-stop toxic diet of sexual music and videos, which was likely to compromise any potential positive effects; and 3) these projects only emphasize simplified messages of prevention, not treatment information. The benefit of this current website is that not only does it focus on the treatment
information and prevention aspects of HIV/AIDS for an African Americans audience, the
effectiveness will be scientifically tested to determine if this modality is a viable format
to improve HIV knowledge for this population.

Wheeler and Miller (1991) also suggested avoiding stereotyping based on
observed or perceived statuses for this population. Hines and Boyd-Franklin (1982)
warned about the problems that result when therapists and policy makers try to design
interventions and solutions based on notions of the “typical” African American family.
For example, contrary to popular opinion, 69 percent of African American families are
not poor (Wilson and Stith, 1991). Only 30 percent of African Americans struggle for
their daily survival. However, it is this subsection of the population that has the highest
percentage of HIV infection and transmission risks (Fullilove, 2010).

Unique cultural practices, values, and behaviors must be negotiated when
developing services for African Americans. The sociocultural realities of continued
disadvantage and difference in many areas, including housing, youth employment
opportunities, planning, and conceptualization must be considered in program design and
service delivery for HIV/AIDS in African American communities. Interventions at the
community level are a planned feature of Phase II to provide local website links that
serve to identify and mobilize resources to address these problems within the African
American community. It should be noted that this website intervention is not an attempt
to homogenize African Americans living with HIV. The level of Afrocentric
acculturation is left to the discretion of the consumer at all times. However, this culturally
sensitive intervention is based upon the recognition of central themes of African
American culture that are present in varying degrees among all African Americans.
Black (1996) highlights several crucial similarities of African Americans, which set them apart from all other ethnic groups. These similarities are:

1. The African legacy – rich in culture, custom, and achievement;
2. History of slavery – a deliberate attempt to destroy the core and soul of African people, while keeping their bodies in servitude; and
3. The victim system – a process by which individuals and communities are denied access to the instruments of development and advancement, and then blamed for low levels of accomplishment and achievement, while treating their successes as anomalies.

These are common experiences of the African in the Americas, whether they lived in the Caribbean, Central and South America, or the U.S (Black, 1996). What sustained people of African descent were the portions of the African legacy that they were able to preserve of their culture. The Afrocentric worldview is another example of a shared commonality among African Americans, which can be used to inform effective psychoeducational interventions for this population due it is resurgence within the African American community (Parham, White, and Ajamu, 1999).

Mullings (2000), attributes the recommitted return toward Afrocentric culture in part as a reaction to the failures of liberal integration, partially as a consequence of the state-sponsored destruction of the left, and in part as a challenge to the apologists for inequality who blame the cause of increasing poverty on African American culture. He reported that within the last decade African Americans have once again become increasingly committed to reclaiming their culture and history. This has taken a variety of forms and is evident in phenomena as diverse as the iconization of Malcolm X, to
renewed interest in African hairstyles, jewelry, and clothing, and the rise of Afrocentric philosophy. Thus, it is a logical step to develop interventions that embrace Afrocentric principles germane to the African American community and the literature’s support of the effectiveness of psychological interventions when they are tailored to meet the needs of African Americans (Tolliver, et al., 1998; and Boyd-Franklin, 1996). Additionally, health care providers who work with this population need to understand African American culture and psychology (Tolliver, et al., 1998).

The Afrocentric Paradigm

Afrocentricity is a paradigm that was developed by Black Studies professor and scholar, Dr. Molefi Kete Asante in the late 1970s. Afrocentricity is based on the idea that African people should re-assert a sense of agency in order to achieve healthy mental, health (Asante, 2003). One of the key assumptions of this paradigm is that all relationships are based on centers, margins and distances from either the center or the margin. For example when people of African descent remove Europeans from the center of their reality, thereby placing themselves at the center of their reality and history, they see themselves as active agents able to act on behalf, or more in tune with their community. Therefore, Afrocentricity serves to activate consciousness, a sense of purpose, which is expressed through the highest values of African culture in the forms of science, philosophy, art, literature, and spirituality for the benefit of African people. In other words, in order to have a healthier sense of self, Asante suggests that people of African descent need to reorient to evaluating and acting upon information from an “Black (African) perspective” as opposed to a “White (European) perspective” (Asante, 2003).
The African worldview emphasizes emotional vitality, interdependence, the oral tradition, harmonious blending, the role of the elderly as important, an extended family system, and collective survival (Parham, White, Ajamu, 1999). Cooperation is valued above competition and individualism. Collective survival is realized through the principle of the basic human unit is the tribe, not the individual. The tribe, or community operates under a set of rules geared toward collective benefit and survival, which can be facilitated by the future networking capabilities of the website.

The African worldview begins with a holistic conception of the human condition. The human organism is conceived as a totality made up of a series of interlocking systems. This total person is simultaneously a feeling, experiencing, sensualizing, sensing, and knowing human being living in a vitalistic world where everything is interrelated and endowed with a supreme life force. The African and African American life styles share a sense of aliveness, intensity, and animation in the music, dance, song, and language. It is this appreciation of this worldview that will inform and set the tone of the website utilizing African-centered universal designs and language. For example, “Keeping it real” is a contemporary reference to the African worldview of maintaining honesty, via collective responsibility to the community. The key feature of sharing honest information about HIV disease serves to empower and uplift fellow African Americans living with HIV. By assisting others continually affirms how African peoples are closely psychologically interconnected and interdependent upon each other in a way of life that involves concern and responsibility towards others.
The Afrocentric paradigm asserts three major assumptions of human beings: 1) human identity is conceived as a collective identity “I am because we are and because we are, therefore I am” (Mbiti, 1970); 2) the spiritual/nonmaterial (soul) component of human beings is just as important and valid as the material component; and 3) the emotional approach to knowing is as valid as the rational path to knowledge (Schiele, 1999).

This paradigm is a social science paradigm based on the philosophical assumption (i.e. worldview) of contemporary African American and traditional Africa. The origins of this worldview, however, are found in traditional Africa, prior to European and Arabic influences. Although these influences of colonization and slave trading altered African societies and cultures to a degree, numerous Afrocentric scholars agree that the philosophical integrity of traditional African culture has survived among continental Africans and among African peoples throughout the Diaspora (Schiele, 1999).

The implication for African Americans is that slavery and the defamation of African culture did not destroy all of the cultural vestiges of Africa for African Americans. In fact, the opposite has been suggested that the social isolation of African Americans created by the institution of slavery and racial segregation, as well as the desire to maintain African traditions, facilitated the preservation of traditional African philosophical assumptions among African Americans (Nobles, 1980; Franklin, 1980; Herkowitz, 1941). These Afrocentrists assert that traditional Africa has remained intact enough to render African Americans a distinct cultural/ethnic group. These scholars also maintain that the use of Eurocentric theories to explain Africans and African Americans is inappropriate and implicitly oppressive because they reflect conceptions of human
behavior developed from European American culture. As a result, Eurocentric theories have historically served to marginalize, and vilify the indigenous worldview of people of African descent. It is therefore necessary to implement and evaluate a more appropriate, Afrocentric model, which may better serve the African American community as it struggles to effectively cope with pandemic HIV.

**Remedy Through Behavioral Ehealth**

Ehealth refers to all forms of electronic healthcare delivered over the Internet, ranging from informational, educational and commercial "products" to direct services offered by professionals, non-professionals, businesses or consumers themselves (McLendon, 2000). Ehealth includes a wide variety of the clinical activities that were traditionally characterized telehealth, but are now delivered through the Internet. Simply stated, Ehealth is making healthcare more efficient, while allowing patients and professionals to do what was previously impossible.

The Internet enables patients to have increasingly immediate access to worldwide medical databases, libraries, conference proceedings, and medical records. They can log onto MEDLINE for original journal articles, access textbook collections, drug databases, diagnostic cookbooks, and disease-specific sites. As a result, patients are taking more responsibility for their healthcare decisions and relying less upon individual practitioners (Ferguson, 1997, 1998). Ehealth empowers individuals by allowing them to make their own informed decisions regarding personal healthcare (Spielberg, 1998). Spheres of expertise traditionally held exclusively by professionals are now open to the public at large. Patients are presenting themselves for treatment, often armed with information they found on the Internet, and are seeking answers to questions based upon that information.
They are also helping themselves and each other, with or without the help of professionals. As a result, the Internet has become a critical tool for gathering health-related information.

Widespread access to the Internet has the potential to improve the health care and quality of life of people with chronic illnesses, including people living with HIV–AIDS (Kalichman, Weinhardt, Benotsch, DiFonzo, Luke, and Austin, 2003). Kalichman, Weinhardt, Benotsch et al. (2003) reported that health-related Internet use was associated with increased HIV disease knowledge, active coping, information-seeking coping, and social support among persons who were using the Internet. Their findings suggest that there is a possible link between using the Internet for health-related information and health benefits for people living with HIV/AIDS, which supports the further development of interventions to close the digital divide in HIV/AIDS care.

The National Health Interview Survey (NIHS) reported that 61% of all U.S. adults have used the Internet for health or medical information and 49% have accessed a website that provides specific information about a specific medical condition or problem (NIHS, 2009). As this trend of increased access and usage of the Internet will likely continue, an appropriate direction to explore meeting the psychoeducational and prevention needs of African Americans living with HIV/AIDS may also be Internet-based. A central focus of Ehealth is the development of low-cost, convenient, step-wise services that are able to address a wide range of issues (O’Donohue and Draper, 2011). For example, most leading hospitals have online informational services (e.g. http://www.mayo.edu; www.thebody.com; Johns Hopkins’ www.Hopkins-aids.edu/ask.html; and Kaiser Permanente’s My Health Manager
In many managed care organizations, informational services are offered as well as some types of direct care through privately accessed parts of the Internet, known as "intranets." With an increasing trend toward employing non-licensed "lifestyle managers" to "coach" consumers via telephone for issues related to smoking cessation, weight management and depression, it will be of interest to see how psychologists will navigate their role regarding eHealth in these organizations. To date, it appears that psychologists are employed as program developers rather than direct service providers for online programs.

While several hundred thousand healthcare sites already exist online, only a few hundred are exclusively web-based that offer unprecedented, evidence-based services and benefit their users. Consumer demand is very high. In 1998, an estimated 60 million adults used the Internet to find health related information (Kaufman, 1999). In a survey of 3,269 Internet users, eHealth users reported that finding disease specific information was their number one application of the technology (Intel, 2000). Powered by demand for prescription drugs, consumer spending for online health goods and services increased from 1 million in 1999 to .8 billion in 2004 (Intellihealth, 2005). The percentage of people searching the Internet for medically-related information was reported at 80% in California (California Healthcare Foundation, 2011). Hogan and Palmer (2005) reported that persons living with HIV who use the Internet for health information seem better informed about HIV/AIDS and report more use of active coping strategies, including information seeking, and greater social support. Although such specifically designed information is not yet available, African American and Puerto Rican men reported that HIV information is an essential component to their health (Hogan and Palmer, 2005).
Previous studies have identified a “digital divide” between African Americans and Whites, with the former having substantially lower rates of Internet use (Jackson, Zhao, Kolenic, Fitzgerald, Harold, Von Eye, 2008). Although African Americans were reported as least likely to use the Internet for health information, researchers reported that this population is catching up, via more use of mobile devices (California Healthcare Foundation, 2011). A survey of African American diabetic patients reported that 89% of participants reported that they would use a computer program to manage their diabetes if it were offered free of charge (Jackson, Batts-Turner, Falb, Yeh, Brancati, and Gary, 2005). This research supports the idea that there is a demand for free, web-based disease management tools for this population. This research project is an opportunity to evaluate how much of a demand there is for Internet information seeking about HIV among African Americans.

A recent exploration was conducted using the phrase, “self-help websites for African Americans living with HIV/AIDS” on google.com and lycos.com, which yielded 1,550,000 and 3,590,000, respectively. Upon closer examination, there was considerable overlap of referred sites and limitations of the websites offered. Here is the following critique of the HIV websites offered for African Americans. Although they are still listed in current search engines, they are no longer available, or outdated. Current sites do not offer up-to-date information or relevant links to African American self-help, community-based organizations that can assist this population with specific prevention and disease management issues. When they are African-centered they only focus on prevention of HIV infection. They also usually address the political activism aspects of HIV advocacy
for the gay, and bisexual community, but lack the necessary components of effective prevention and disease management for heterosexual African Americans.

Current websites are not informed by culturally competent, African American experts for effective HIV disease psychoeducational content regarding effective prevention and treatment. They do not offer evidence-based treatment information and/or treatment strategies. Many of the sites’ validity are influenced by pharmaceutical bias, via advertising to endorse the use of their drug(s). Overall, Western-oriented, websites lack cultural sensitivity due to the fragmented approach to disease management vs. the African-centered, holistic approach to disease management unique to the treatment and prevention needs of this population. Additionally, these sites were found to be sterile, esthetically unattractive, and not user-friendly. Lastly, the few that are user-friendly and evidenced-based, they lack the necessary means to assess their efficacy regarding consumer acceptability, via online assessment instruments, and relevant data collection, which can lead to improving the technology and services offered.

HIV Information for African Americans Using an Afrocentric Web-Solution

An efficient, cost-effective way to distribute information to African Americans is to develop a website that would provide psychoeducational content regarding prevention and disease management for HIV/AIDS, as well as information regarding the above co-existing concerns of depression, and life style components of living with HIV/AIDS from an Afrocentric perspective. The advantages of this website would be that it is culturally sensitive because it would build upon the strengths of the African American culture, which directly corresponds to the African worldview described by experts in the field of Afrocentricity (Asante, 2003; White, 1984; Nobles, 1972; and Mbiti, 1970).
Although this website will be accessible to all persons living with HIV, the focus of this website will be for African Americans who present with unique needs and concerns, which have not been adequately addressed in the treatment literature. These needs include: stress, stigma, alienation, depression, and accessible prevention and treatment information.

A preliminary pre-doctoral study was conducted by this same author, which consulted HIV+ African Americans and HIV/AIDS experts to test the feasibility and acceptability of creating an Afrocentric website for HIV+ African Americans. HIV/AIDS experts reviewed the website’s prototype separately and then provided feedback, which were incorporated into its current design. This prototype was then tested using 17 HIV+ African Americans. A total of three focus groups were conducted at a community HIV/AIDS Center. The finding of this study revealed an overwhelming need for accurate and up-to-date HIV/AIDS treatment information delivered in a culturally sensitive manner. The more relevant the information offered to the African American community the more compelled they reported to engage the information. There was an overall awareness of the devastating toll that pandemic HIV/AIDS is having among the participants. Moreover, they expressed a need for more information regarding statistical impact to their community, especially long-term impact of treatment issues. These needs were related to self-efficacy and self-empowerment.

This study demonstrated a need to also know co-occurring illnesses prevalence and prognosis in relation to being HIV positive. For example, the lifestyle diseases of high blood pressure and diabetes disproportionately impact the African American community. It would be useful to provide in the future modules of how to cope with
being HIV+ and these conditions as expressed by the need for holistic disease
management strategies such as diet, exercise, and stress management. Participants also
expressed a need to know how to manage medication side effects. Although it was not
addressed in this study, or the subsequent study, the history and current epidemic of IV
drug use continues to be a contributing factor to increased HIV infection for the African
Americans. Nearly half of the men contracted the virus through IV drug use.

Lastly, psychological treatment issues are concern for this population, particularly
depression and anxiety. There was also an expressed need to psycho-social support in the
form of a professionally supervised online chat room. Participants in this study
appreciated a need to not be socially or spiritually isolated in their fight against
HIV/AIDS. Rather, they recognized a need for spiritual and social support as well as the
comfort of networking among their own.

Overall, the website’s prototype was generally well-received by both the
consultants and participants. The information from this study provided by patients and
professionals have proved invaluable with informing the present study. The overall
strengths of the website prototype are that it provides engaging and helpful information
for an underserved population in a culturally sensitive, easily understood manner. More
importantly, the website’s usefulness may be enhanced with brighter coloring (beige and
tan vs. black background), culturally relevant imagery, larger text, and use of layman
terms supported by a glossary link. Although there is a recognized need for culturally
sensitive, web-based information, this sample of African Americans of lower socio-
economic status indicated that they would not pay for such services. Another limitation of
this study is small sample size which is by no means a representative sample of the African American communities throughout the U.S.

The current study is informed by the above research, which will be implemented through the above recommended changes such as: further simplification of website’s language, using more layman’s terms to explain HIV/AIDS disease process, treatment, and prevention. When technical terms cannot be simplified they will be explained in the simplest terms possible and use examples. There will also be a glossary link to enhance and support the user’s HIV knowledge base. Also to increase the website’s ease of use, a website map will be included as a link to the introductory page. The font will also be made larger and the text will be divided into smaller sections to enhance it is readability.

The style and presentation of the Afrocentric esthetics will be updated to reflect current African American cultural icons of hair, dress, complexion, and symbolism using digital images of contemporary African Americans. The website will also be updated to include more relevant statistics regarding the impact of HIV/AIDS, co-occurring conditions (e.g. high blood pressure, diabetes, heart disease), as well as their prognosis with and without treatment. Lastly, links to local resources for people living with the HIV/AIDS virus will be provided on the website.

Webpage Design Protocol for the Current Study

Empirically supported web-based treatment information for co-occurring psychological conditions will be available to the user, via a link to TriWest Healthcare Alliance (http://www.triwest.com/en/beneficiary/behavioral-health/resource-center/emotional-well-being/). TriWest is a self-help website that offers empirically supported treatment strategies for the psychological treatment of such conditions as,
Description of the prototype for “Positive Living: HIV Facts on the Web for African Americans” is as follows:

I. Psychoeducation – first quiz will be offered, via “Survey Monkey” as the last form to be completed out of three online surveys. The quiz will assess their HIV knowledge before reviewing the website. The quiz will cover the following information that is offered in the website’s content:

- What is HIV and AIDS?
- What are the different types of HIV?
- Longevity and living with HIV
- Safe sex practices and transmission risks.
- Disclosure of HIV status.
- What is HAART?
- Initiating HAART therapy.
- How do you cope with common side effects of medication?
- How to talk you health care provider;
- How to maximize your health care appointment; and
- Taking care of your mental health.

Once the participant finishes the last survey they will then be directed to the website’s url - HIV BASICS page at http://positiveliving.jasonwollam.com. Although the Home-page of the website will appear first, the HIV BASICS page is easily navigated to by clicking on the drop-down menu next to the top of the page, near the HOME button. Each webpage uses a template of Afrocentric aesthetics consisting of black and dark
II. Learning About HIV from an African-centered perspective – Use of Afrocentric principles in the development of disclosure strategies and safe sex practices concerning collective responsibility, as well as offering appropriate examples of effective coping strategies (e.g. developing support systems through community and church, and stress management):

- link to African American community organizations that are supportive of persons living with HIV, family members and loved ones;
- link to community health care facilities that provide free HIV testing, counseling, and treatment to those who are eligible;
- link to community organizations that advocate for the rights of HIV regarding employment, housing and treatment assistance.

Goals of the Afrocentric, Web-Based Intervention

The goal of phase I is to complete the development of the Afrocentric website in such a way that it is easily understood, and engaging. The second goal of the Afrocentric, web-based content is to equip the user with the essential points of knowledge regarding HIV/AIDS prevention, disease process and treatment. The following section will outline each of these goals of the present study and how they will be addressed in the website, followed by a brief rationale of each strategy.

Goal 1: The website will give the user an understanding of HIV basics and transmission prevention. Using easily digestible and engaging information, the website will inform the participant about HIV/AIDS basics, and HIV prevention, (e.g. Safe Sex
Practices). It will also teach the user about treatment information and treatment options, and inform them about the challenges of potential lifestyle changes that are associated with living with HIV.

Goal 2: The website will teach the user about antiretroviral medications and effective treatment adherence strategies. This goal will also be accomplished by linking to psychoeducational information about antiretroviral medications and when to initiate antiretroviral therapy. For example, the patient’s viral load and CD4 count are important indicators of prognosis and two of the most useful ways to monitor response to treatment (Bartlett, Gallant, and Pharm, 2010). If the patient’s CD4 count is low and the viral load is high, then prognosis without treatment is poor. If the patient’s CD4 count is high and the viral load is low, prognosis is good. A CD4 count between 600 - 1,200 (30% to 60%) is considered within the normal range of good health (Bartlett, Gallant, and Pharm, 2010). However, a CD4 count of 500 or less is an indication that moderate damage has been done to the patient’s immune system. At this time it is usually recommended to initiate or resume a regimen of HAART (U.S. Department of Health and Human Services Treatment Guidelines, 2011).

Goal 3: Users will also be taught about the importance of maintaining optimal mental health and living with HIV, as well as links to empirically supported ways to cope with mental illness, as well as how to provide appropriate support to a psychologically distressed loved one. For example, participants will learn about depression and its prevalence among African Americans living with HIV/AIDS, as well as effective treatment options.
Purpose and Rationale of the Proposed Study

The purpose of the current study is a Phase I Treatment Development Research project as described by Hayes, Barlow, and Nelson-Gray (1999). Phase I is a continuation of the above-described focus group study regarding the feasibility of the website’s prototype as informed by experts. The current study is the second part of that feasibility testing, and refinement of psychoeducation and treatment procedures. Thus, the current study will include two distinct phases. The first phase involves the completion of the website’s prototype, followed by a second review by the expert consultants. The second part involves pilot testing the treatment outcome of the website.

Rationale of the proposed study was to further test the content and construct validity of the Afrocentric website, HIV Facts on the Internet for African Americans. This endeavor is a significant advancement in current web-based psychoeducational interventions for this unique population for the three following reasons:

1. Focus groups and expert consultation will ensure that the website developed will have both content and construct validity. The final stage of development of the intervention will be the main focus of the current study in order to ensure that the finished product will be accurate, engaging and culturally relevant.

2. The website will be empirically evaluated for efficacy as well as any possible iatrogenic effects.

3. The website fills a need in a relatively unexplored population. Although a lot of attention has been devoted to the HIV/AIDS gay, Caucasian population,
there is very little literature about the psychosocial and/or psychoeducational web-based treatment needs of African Americans living with HIV/AIDS.

**Hypotheses.** The current study will investigate the following hypotheses after both content and construct validity of the website has been established by the experts, via a second review by the experts in the field of HIV/AIDS:

- **Hypothesis 1:** Website participants will demonstrate greater knowledge of HIV prevention at post-test.
- **Hypothesis 2:** Website participants will demonstrate greater knowledge of HIV disease process and treatment at post-test.
- **Hypothesis 3:** Website participants will report high consumer satisfaction regarding the website’s ability to address the psychoeducational treatment needs for African Americans about HIV in a culturally relevant manner.

**Methods**

**Phase I: Content and Construct Validity**

The objective of this part of the study is to further assess the content and construct validity of the psycho-education information offered in the website’s content and design. Content validity will be evaluated through the use of expert consultation. The experts will be asked to review the website’s content to provide comments about its validity.

The experts consist of an HIV/AIDS physician and other health care professionals in the HIV/AIDS field. Dr. William O’Donohue and Dr. Trudy Larson will serve as the primary expert consultants. Dr. O’Donohue is a professor at the University of Nevada Reno. Dr. O’Donohue specializes in evidence-based therapies and has written and edited
numerous books and scholarly articles in this area. A recent example is, “Stepped Care and E-Health: Practical Applications to Behavioral Disorder (2011). Dr. O’Donohue will consult on the behavioral activation, treatment of depression portion of the website.

Dr. Trudy Larson will provide expert consultation for information offered in the HIV/AIDS medical treatment options portion of the website. Dr. Larson has over 20 years of experience with treating HIV/AIDS patients in the Reno/Sparks community.

The overall Afrocentric layout and presentation will be addressed by Geralda Miller. Ms. Miller is an African American journalist for a local newspaper. Ms. Miller is also the spiritual liaison for the Reno Sparks African American community and has completed her master’s thesis on African American history. The website’s layout concerning search engine feasibility and organization will be addressed by Jason Wollam. Mr. Wallom specializes in web design specific to increasing it is hit-rate based on that website’s organization and content. Mr. Wallom also has experience designing websites to accommodate mobile devices (e.g. cell phones and tablets). He was recently the project manager for updating and converting Toshiba’s online store to function on mobile devices. Mr. Wallom will also maintain the server to host the website. He is an experienced web designer who understands the importance and need for such research.

Lastly, as a long-term survivor (23 years) of living with HIV/AIDS, Dr. Dorothy Kleffner will provide expert consultation concerning the overall content, layout and feasibility of the website’s design. Dr. Kleffner has established herself as an outspoken HIV/AIDS activist and advocate regarding women issues related to HIV treatment and patient’s rights. She has served on numerous boards such as, the California State Office of AIDS (founding member), USA Positive Women’s Network, the Global Network of
People Living with HIV/AIDS, and the San Francisco HIV Planning Council. Prior and concurrent to the positions listed above, Dr. Kleffner has also held numerous volunteer positions planning and implementing conferences, retreats, and educational campaigns, both specific to women and regarding HIV in general. These included volunteering with WORLD, the Project Inform hotline, Woman Power in Helena, MT, the Fight Back class for people living with HIV in San Diego, CA, and two (2) talks at International AIDS conferences. Dr. Kleffner became very involved in the science of HIV, and worked at transmitting this information to those living with HIV/AIDS in an understandable way. Dr. Kleffner brings a rich knowledge base as a long-term survivor, and continues to work to pass on that information.

The expert consultants were given a copy of the entire website prototype, or individual pages based on their area of expertise, and were asked to provide feedback regarding the appropriateness of the content and its potential for increasing HIV knowledge. Construct validity was evaluated by the website’s ability to educate an adult sample of 17 African Americans about the complexities of HIV prevention, disease process and treatment.

Phase I of this study ended when the website’s construction incorporated the above described design changes. After the changes were made, phase II commenced with a second review by the consultants to ensure accuracy and appropriateness of the website’s information and presentation, followed by phase II, testing the website.
Phase II: Subject Recruitment and Data Collection Procedures

Phase II examined the effectiveness of the website using a one-group design of pre and post evaluations comparing the participants knowledge of HIV/AIDS regarding prevention of disease transmission, disease process and treatment. The website was also rated for consumer acceptability, satisfaction, and cultural sensitivity.

Recruitment for participation in this research opportunity was done, via word-of-mouth among African American Professors and students at the University of Nevada, Reno, University of South Carolina, California State, Bakersfield, Bakersfield Community College, and at three (3) local Black Churches in Bakersfield, California. Participants were given URL address to the Survey Monkey website, via e-mail. Once the subject reaches the site he or she will completed four forms: the informed consent; the Demographics survey; the Black Racial Identity Scale (RAIS-B) survey; and an HIV Quiz. This information was electronically and confidentially filed away in the Survey Monkey database and downloaded later for analysis. Once they completed the Survey Monkey portion of the study they were directed to the study’s URL - http://positiveliving.jasonwollam.com/. Once participants finished reviewing the website, they were directed back to the Survey Monkey website to complete a follow-up HIV Quiz and a consumer satisfaction survey.

After completing the assessment battery (except the consumer satisfaction items) the participants (8 African American women and 9 African American men) reviewed the content of the website. Participants were free to interact with the entire website (e.g. HIV Basics, HIV Statistics, HIV Treatment, etc.) for a period of 2 weeks (14 days). All
participants had access to 175 pages of web-based information about HIV disease. Each participant accessed the website by creating an account with a username / password format to ensure the privacy of the participant and the security of the website.

Results

The results of this research will be provided in three sections: 1) content validity and cultural sensitivity; 2) followed by the quantitative and 3) qualitative findings.

Content validity and cultural sensitivity were evaluated by summarizing the recommendations provided by the expert consultants. Experts provided valuable input during the website’s phase I development portion of this project. The following professionals are well-known in their perspective fields of expertise: Dr. William O’Donohue; Dr. Trudy Larson; Geralda Miller, M.S.; Jason Wallom; and Dr. Dorothy Kleffner.

Dr. O’Donohue provided valuable feedback on the website’s layout, and content regarding what topics it would address such as, HIV Basics, HIV Prevention, and overall mental health treatment aspects of HIV disease management. More specifically, Dr. O’Donohue provided consultation on the website’s content to ensure that the psychological aspects of HIV disease management were evidence-based. As a result, specific links to “treatment options” were created to address the depression and anxiety-related treatment needs of HIV disease. These links lead to evidenced-based, online resources such as, (Triwest.com) that specializes in cognitive behavioral treatment strategies concerning psychological disorders of depression and anxiety.
Dr. O’Donohue’s suggested linking the website to information more interactive and visually oriented. As a result, video demonstrations were also incorporated into the website’s content. For example, when the topics of male and female condoms were addressed in the HIV Basics section, (Safe Sex Practices page), both components concluded with a link to a video demonstration provided by an expert in the field of HIV prevention. Similar video links were provided for an additional explanation of how HIV attacks the body in the Treatment (Antiretroviral section of the website.

Dr. Trudy Larson provided important guidance regarding the website’s overall content related to the medical information pertaining to standard medical practices, care and medications related to effective HIV disease management. Dr. Larson was instrumental in checking the website’s content contained up-to-date and accurate HIV medical information.

Geralda Miller, M.S. consulted on the website’s layout and esthetic design to ensure that it had an Afrocentric orientation and appeal. Ms. Miller provided valuable input as to the website’s arrangement to create a warmer, more inviting look and feel concerning its overall design and flow. Ms. Miller also consulted on the finished design of the website, stating “I think you did a great job on this website. I especially like the overall look – the parchment paper, hieroglyphics, and images of African Americans. It shouts Afrocentricity! There is no way that someone clicking on this page would not know that it is targeting African Americans.”

Once the mud clothe pattern and colors were selected they were brought to webdesigner, Jason Wollam to incorporate them into the color scheme and template’s theme of the website. Mr. Wollam was able to masterfully superimpose a papyrus,
parchment-like design over the yellow mud clothe background. Additional black hieroglyphic lettering was also added. The literal translation is “Enter here in peace”. These can be seen in website’s side margins as an esthetic accent, which adds to the Afrocentric credibility of the design regarding historically significant achievements of ancient North African culture. Mr. Wollam designed and set up the Joomla templates, participant username and password login process, as well as hosted the website on his personal server without charge for the duration of this research project. Hence, the website’s formal name, http://positiveliving.jasonwollam.com.

Mr. Wollam also provided guidance on the website’s navigational organization of the content, and increased traffic to the site. Mr. Wollam had this to say about the Positive Living website, “The Positive Living is the result of very important research endeavor within the field of access to easily understood HIV information, with which he was proud to be affiliated. Mr. Wollam described the website’s functionality and straightforward navigation as designed to facilitate the user’s learning experience, as well as pique their interest on the same website of similar topics. For example, each page contains a brief summary of easily accessible links related to the topic of that page. This enables the user to easily regain their original starting point for review of information, or to proceed to more information. The user is free to continue exploring a related topic or to move on to a different topic, which is easily done by clicking on the perpetually present main menu headings (e.g. HIV Basics, Nutrition, Statistics, Treatment, or Resources). The website also allows the user to focus on the information presented without being distracted by flashy advertising or other “annoying” pop-ups. Concerning the website’s capability of being found and web traffic, search engines will not have a
problem finding this site as it contains the popularly searched terms utilized in HIV search engine language.

Mr. Wollam also noted that the volume of content (174 completed pages with more to be completed in the future), and additional menu items produced by Mr. Niccolls has demonstrated this researcher’s commitment and skill to maintaining this website long into the future. Mr. Wollam concluded his remarks by stating that he is confident that Mr. Niccolls will be able to maintain Positive Living with minimal technical assistance.

Dr. Dorothy Kleffner shared the following endorsement of the Positive Living website, “The beautiful images are a warm invitation into the website, the look and feel are inviting. The website strikes a solid tone when talking about women's issues around HIV. There is no tinge of the guilt or judgment so often inflicted on women for simply having the virus, or for considering pregnancy or sexual activity after infection. It clearly states the medical facts around pregnancy and HIV, indicating that the risk to mother and child is very low with appropriate medical care. The radiant picture of a pregnant black torso brings an emotional warmth to the topic, backing up the hard facts with a beautiful sense of reality.

The website doesn't dance around the medical facts, giving a hard truth when necessary. I was encouraged to see a call for Anal PAP tests for women, so often overlooked, and this speaks to the thoroughness of the information presented.

The harsh facts about women of color and HIV are particularly well handled, matter of fact and detailed. The biological factors that increase susceptibility, as well as the poverty, violence, and lack of opportunity that feed risk-taking behaviors just to meet
basic needs are well described. For topics ranging from safer sex to concentrations of HIV by region, the website empowers the reader by providing solid information.

Lastly, resources for women are all too sparse, but the website cannot link to that which doesn't exist. By directing them to such places as WORLD and the Positive Women's Network, the website gives women a place to begin.”

In summary, the research goals concerning the website’s preliminary content validity were met to test its acceptability among African Americans. The above experts agree that website’s information is evidence-based, accurate and up-to-date. This information is also presented in an easily understood format that is culturally sensitive.

Phase I of this study completed the website’s construction by incorporating the above described changes. After the changes were made, phase II involved a second review by the consultants to ensure accuracy and appropriateness of the website’s information and presentation, followed by phase II, testing the website.

Description of Website Prototype

The following section contains a description of the Positive Living website in current form, as reviewed by the research participants.

The website begins on the HOME page, which welcomes the user with a warm beige and tan mud clothe pattern superimposed as the background for the text. The Home page contains the Purpose, Goals, and Mission Statement, as well as the Medical Disclaimer and Privacy statement.
All of the imagery selected for the website’s pages were chosen as they are most effectively convey the information or theme on the perspective page. This is seen in the example of the first photo of the woman with very African features wearing a black t-shirt with white and red lettering, “A World Without AIDS is Possible”. Her shirt reflects the popular mantra from the HIV culture concerning treatment as prevention (International AIDS Conference, Toronto, Canada, 2006). It also speaks to the empowerment gained from timely and consistent HIV treatment that can reduce a community’s collective viral load, therefore reducing infection rates down to zero. The women’s face is stern, looking directly into the camera, implying a let’s get down to business as she is holding an ink pen. This photo was selected out of many choices because African American women and women of color, worldwide are the new face of HIV due to their disproportionately high infection rates (CDC, 2011).

The main menu is centrally positioned at the top of the page under a banner containing a collage of African American men and women’s faces and hands interlaced with Kente clothe. Kente clothe is a prominent icon of African and African American culture and sets the tone of Afrocentricity. The main menu is the prominent feature and is easily accessed throughout the site as a key navigational tool. At all times the user can easily access the main menu containing its main topics. Each page also offers a summary menu of relevant items to help the user navigate the section was greater ease, as well as explore related topics. The website is also internally linked to ensure the user is exposed to all of the information as it relates to each other.

Moving from left to right, the next menu item is the HIV BASICS page. This section is comprehensively researched and presented in layman’s term for easy reading
and comprehension. This section contains important information about HIV disease and its prevention of transmission. It covers such key topics as: longevity; disease progression; explanation of the difference between HIV and AIDS; HIV subtypes and their prevalence; HIV life cycle; opportunistic infections (OIs); how to prevent or treat the most common OIs; important aspects of the immune system and how HIV impacts key organs; transmission risks and what to do in the event of a high-risk exposure; tips on dating as an HIV+ person, evidence-based Safe Sex Practices, as well as tips on how to disclose your status to a potential partner.

Although the Nutrition section of the website is not complete, it’s worth noting that the Avoiding Toxins page is outlined. The purpose of this page is to highlight the commonly occurring toxins encountered in one’s food and environment, and how they impact the immune system.

The next item on the menu is the STATISTICS section, which was added due to the feedback of earlier research pertaining to the construction of this website. African Americans wanted to know specifically how this pandemic was impacting their community regarding prevalence of infection rates. This section informs the user about the specific infection rates among African American men and women. By providing a brief history of HIV in the Black community, it explains some of the causes of the high rates of infections. This section also contains tips for African American women as far as pregnancy and overall treatment tips. This section is also linked in the treatment section as well to ensure the user’s exposure to the information.

The TREATMENT section addresses the complicated aspects of treatment regarding HIV disease in an easily understood format, including animated videos (e.g.
how HIV attacks T-cells) This section explains what to do from beginning of an HIV+ diagnosis to survival tips for the more treatment experienced. Included in this section are the mental health aspects of HIV disease, as well as helpful links to evidence-based coping strategies for: depression, anxiety, and isolation due to stigma. This section also contains helpful information to assist with the navigating the complex medical system concerning self-advocacy and patient’s rights to ensure optimal care.

Lastly, the RESOURCES section is still under construction. Although this section is not finished, the necessary links have been established. For example, how to find a doctor, complete with helpful tips and a link on how to find an HIV provider in your area, (www.aahivm.org/referrallink/exec/fromAdvSearch.aspx?bs=11233).

Quantitative Results

Review of the website was examined through the use of quantitative and qualitative statistics based on website exposure to obtain HIV information. The demographic data was summarized using descriptive statistics.

A total of 17 African Americans (8 women and 9 men) were evaluated on their knowledge of HIV prevention and treatment prior to and after having access to a website designed to inform users about this disease. Participants’ ages ranged from 33 to 63 years, with a mean age 46 (SD = 7.27) for the women and 44 (SD = 6.85) for the men. The educational experiences of the participants ranged from high school diploma to graduate school with a professional degree. The majority of participants in this study reported having had more than a 4-year degree of college education.

Participants’ income ranged from less than $15,000 to $90,000 per year. The average annual income for the women was $46,000 (SD = 26.89). The average annual
salary for the men was $54,000 (SD = 25.55). Participants were from the various regions of the United States such as, West Coast (California), North East (New York and New Jersey), Midwest (Missouri), and the South East (Maryland and Virginia).

Prior to beginning their interaction with the website, participants were asked to rate their ability to use the Internet. Only one participant rated himself as “uncomfortable” with using the Internet. All other participants rated themselves as either “very comfortable” or “expert”. All participants indicated that they had frequent access to the Internet, either at home or during work hours. Participants were also asked to rate themselves regarding their knowledge of HIV prevention and disease treatment. Responses ranged from “I know very little” to “I know enough to inform others”.

**Hypothesis I:** Website participants will demonstrate greater knowledge of HIV prevention at post-test.

The purpose of the website is intended to raise awareness and educate. A difference in means test with paired sample data was performed. The table value for a one percent level of significance (p-value = 0.008), (df = 7). The data revealed that the knowledge of HIV prevention is significantly greater than before they used to website. The average pre-test score for the men was 41.6% (SD = 9.3) while the average pre-test score for the women was 48.4% (SD = 9.3). The average post-test scores for the women increased to 52.8% (SD = 14.8), but not as much as the average post-test score men, 60.5% (SD = 13). An overall, twenty-eight percent (28%) increase of knowledge was reported. These findings hold at a one percent level of significance, so these findings are highly significant.
In other words, there is only about an 8 out of 1000 chance of error for incorrectly concluding from the sample that this web-based educational platform will significantly improve education and promote greater awareness about HIV. The results of this sample point to a highly significant impact being attributed to use of the website as a tool to improve knowledge of HIV prevention.

**Hypothesis 2:** Website participants will demonstrate greater knowledge of HIV disease process and treatment at post-test.

Further analysis was conducted on the test questions that focused on the prevention and disease treatment. Statistical relevance was found at the 10 percent level of significance for the prevention questions. The critical value is 1.415 (alpha=.10, df=7) compared to 1.73 for the calculated test statistic. This lends support to the claim that those who use this HIV online resource gain valuable information, which can be utilized to reduce the incidence of HIV in this population.

**Qualitative Results**

**Hypothesis 3:** Website participants will report high consumer satisfaction regarding the website’s ability to address the psychoeducational treatment needs for African Americans about HIV in a culturally relevant manner.

Qualitative analysis of the participants’ responses on the Customer Satisfaction Survey was conducted. Overall, the website was well-received by the study’s participants. Each participant was asked to rank the website on several criteria using a Likert Scale (1 to 10), with “10” being the most favorable and 1 being the least favorable. Participants rated the website as an overall 8.9 (SD = 1.2). The female participants ranked it at higher rating, almost 9.2 (SD = .8), while the men rated it at an 8.8 (SD = 1.7).
Concerning the website’s ranking as user-friendly, the women found it easier to use than the men, 9.1 (SD = 1.1) vs. 8.2 (SD = 1.7), respectively.

The men were found to be more critical than the women regarding the website’s navigation and search facilities, 7.5 (SD = 2.5) vs. 8.8 (SD = 1.2), respectively. The men were also found to be more critical than the women regarding the website’s ability to be easily understood 8.2 (SD = 1.9) vs. 9.6 (SD = .5). This was also found true when it came to ranking the site’s appeal and design. While the female participants rated the site’s appeal and design at a 9.5 (SD = .7), the men rated it lower at an 8.2 (SD = 1.8). When it came to using the site in the future the female participants were found to be more willing 9.1 (SD = 1.7) vs. 7.7 (SD = 3), as rated by the male participants. All of the participants reported they would recommend the website to a friend or family member (over 9). No significant difference was reported between the men and women on their willingness to get tested, 6.8 ((SD = 13.4) and 6.3 (SD = 13.9), respectively. However, they both conveyed a high degree of willingness to get treated, men at a 9.7 (SD = .6) and women at almost a 9.9 (SD = .3). Although the results of this study indicate a below average willingness to getting tested, these participants demonstrate an increased willingness to obtain treatment. This latter finding is an important step in the direction of long-term survival regarding HIV disease among the African American community.

Discussion

A Phase I Treatment Development Research project as described by Hayes, Barlow, and Nelson-Gray (1999) was conducted as a dissertation project. As a continuation of a phase I prototype of the Positive Living website, the current study is the second part of that feasibility testing, and refinement of HIV web-based, psychoeducation
and treatment procedures for African Americans. Thus, the discussion of this study will describe two distinct phases. The first part of the discussion involves the feedback by the expert consultants. The second part describes the results of the pilot testing the treatment outcome of the website.

Overall, the feedback from the expert consultants was favorable. Their input assisted with the further development of the website’s prototype. Much of it was successfully incorporated into the site’s design and language. However, the incorporation of additional photos was hindered by limited funding. Although it would have been ideal to incorporate more actual photos of people into the site’s esthetics, most people declined to be affiliated with a website so strongly associated to HIV disease. However, none of these challenges proved insurmountable in the completion of this important project.

The suggestion of creating links to video demonstrations to explain technical aspects of HIV disease were used to enhance the website’s comprehension. These features were described as helpful and informative by experts and participants alike. The overall esthetic of the site was also received as warm, and engaging by participants and experts. Regarding the suggestion of adding more resources, that will be reserved for future research projects.

This research endeavored to do what it set out to do. It developed an evidence-based, culturally sensitive website for African Americans that was specifically designed to address the psychoeducational needs regarding HIV disease prevention and treatment for this population. The findings of the data are highly significant regarding its ability to effectively educate this community about HIV disease.
The overall high rating of the website at almost 9 out of 10 is also highly significant in that it holds promising potential for being an effective tool to increase awareness among a community that has been found to have very little resources regarding HIV education and outreach. The construction of an evidence-based, socially acceptable, culturally sensitive website that has the potential to be received by the African American community is considerable achievement. When considering the task of doing community outreach and providing accurate information that will be able to convey important information in a relevant manner to the community most negatively impacted by HIV disease, this can be a significant tool to help achieve those goals.

One limitation of this study is the small number of participants, which limits the ability to generalize these findings to the rest of the African American community. However, the website’s general appeal and likeability among these participants holds promise as a viable tool to promote future HIV educational outreach and awareness in an Afrocentric format.

**Limitations of this Study**

The primary limitation of this technology is, although it provides much-needed information to this under-served population, it **does not give medical advice or psychotherapy**. However, does provide information and links to credible sites such as, WebMD and TriWest Alliance, which use a step-care approach to psychological treatment. A limitation to this approach is that it does not provide individualized, client-centered care, which is more amenable to individual needs of the patient.

A second limitation concerns the participants of this second phase of research. Although the first phase was conducted with African Americans who are HIV+, this
second phase did not include persons living with HIV due to the current limitations of the Internet server’s ability to secure the data regarding their HIV status in a confidential manner sufficient to satisfy HIPPA and IRB requirements at this time. However, the website’s application to HIV+ African Americans has been adequately established in the earlier study. Considering the overall goal of the website, HIV Facts About HIV for African Americans, can be used by all members of this community to increase their knowledge of this challenging disease. Concerning the small N of seventeen (17) participants, statistical power was low. However, this was not a concern of the second phase of this research project whose purpose was to explore statistical trends. Another limitation of this design was there was no randomized control group, which was also appropriate for phase I design research. At this time it was the intention of the researcher to continue to confirm the readability and cultural relevance of the website’s content. This continues to be a promising area with enormous future potential as many HIV/AIDS Centers are recognizing the need to equip their facilities with Internet ready computers and training for this very reason.

Although this website is Afrocentric in its design regarding treatment intervention there are several questions that this study was unable to answer such as:

- How does the website compare to other en vivo psychoeducational website that offer prevention and treatment information about of HIV?

- How does the website assist severe, end-stage AIDS patients?

- Which African Americans will be most likely to use this website?
At the conclusion of this study we will not be able to conclude that this website will generalize to all African Americans living with HIV/AIDS. However, the development and testing of this website allowed for systematic effectiveness trials as described by Hayes, Barlow, and Nelson-Gray (1999).

Future Research Implications

There are several important benefits to completing this study. First, this study was the first of its kind to examine the Internet, psychoeducational needs of African Americans concerning HIV disease. Although African American are the fastest growing subgroup in the U.S. with HIV/AIDS, they are the least studied to determine their psychoeducational prevention and treatment needs. This study can serve to further define these needs in a cost-effective and very affordable manner for the user and the health care community to better target outreach, prevention and treatment interventions. Another benefit of this study is that it assisted with the development of effective prevention strategies that can be easily disseminated among isolated populations of African Americans, particularly those living in rural areas. It can be accessed at any computer-equipped, Internet-ready, health clinic, hospital, public, local library or from the privacy of one’s own home. The availability of privacy when accessing the website provides a less stigmatizing experience for the user. Patients will have 24-hour access if they experience problems, such as coping with nausea, anxiety or depression.

Another important implication of this study is that it shows potential as a means of assisting African Americans with effective transmission prevention, disease
management and self-care, which has important prevention benefits to this community overall.

Regarding the demand for such a website, African Americans make up 13 percent of the U.S. population, but account for 51 percent of 56,000 newly diagnosed HIV cases each year (Kalib and Murr, 2006). Another factor that may contribute to the website’s appeal is that it can be understood and used throughout the English speaking African Diaspora. For example, additional subpopulations living in Great Britain and South Africa may benefit from this website. Once the website completed and scientifically tested for efficacy with this population, awareness about this website can be further increased by sending letters and brochures to AIDS clinics and doctors, particularly African American doctors who specialize in treating people of African descent. It can be posted as a flyer in African American churches and community centers in predominantly Black neighborhoods. It is also the hope that the results of this research will be published in high profile journals. Other ways of communicating the website’s availability and efficacy would be to give talks at professional conferences, send press releases to Black media sites such as Black Enterprise, The Source, Jet, Ebony, BET, and the Tavis Smiley Show. It can also be posted as a link to search engines, and the following popular African American websites such as: Balm in Gilead (www.balmingilead.org); Black AIDS (www.blackaids.org); HIV InSite (HIVInSite.ucsf.edu/InSite.jsp?page=li-06-02); National Minority AIDS Council (www.nmac.org); NPIN Topics-African Americans (www.cdcnpin.org/scripts/populations/afram.sap); and Office of Minority Health (www.omhrc.gov/omh/aids/aidshome_new.htm). Lastly, based on the favorable response
to the website from the experts and participants, it will likely begin to spread through word of mouth. A common question of the participants was when will the website be available to use? This author can answer in confidence, “Now.”
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Addendum A

Measures:

Demographic Questionnaire:

1. Age/Gender
2. Socioeconomic Status
3. Level of Education
4. Location of Internet access (e.g. home, work, school, public facility such as a library or Internet café).

HIV/AIDS Quiz: Test Your HIV IQ is developed from the HIV/AIDS information regarding transmission prevention, disease process, and treatment offered by the website. This quiz consists of combination of 40 multiple choice questions in which the participant chooses the correct answer, “A”, “B”, “C” or “D”.

Consumer Satisfaction Data:

1. How user-friendly is this website (Likert Scale from 0 - 10)?
2. How would you rate the navigation and search facilities?
3. Was the information presented in a way that was easy to understand?
4. Overall, was the look and design of the site appealing and inviting?
5. Would you continue using this website for HIV information?
6. Would you recommend this website to a friend or family member who needs information about HIV?
7. How likely are you to get tested for HIV?
8. If you were to test positive for HIV how likely are you to get treated if you were determined by a doctor to need it?
9. What other kinds of information or services would you like to see offered on this site?

10. Other comments:

Black Racial Identity Attitude Scale (Form RIAS-B) by Janet Helms and Thomas Parham (1990), Social Attitudes Scales when administered.

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1. I believe that being Black is a positive experience.

2. I know through experience what being Black in American means.

3. I feel unable to involve myself in White experiences and am increasing my involvement in Black experiences.

4. I believe that large numbers of Blacks are untrustworthy.

5. I feel an overwhelming attachment to Black people.

6. I involve myself in causes that will help all oppressed people.

7. I feel comfortable wherever I am.

8. I believe that White people look and express themselves better than Blacks.

9. I feel very uncomfortable around Black people.

10. I feel good about being Black, but do not limit myself to Black activities.

11. I often find myself referring to White people as honkies, devils, pigs, etc.

12. I believe that to be Black is not necessarily good.

13. I believe that certain aspects of the Black experience apply to me, and others do not.

14. I frequently confront the system and the man.
15. I constantly involve myself if Black political and social activities (art shows, political meetings, Black theater, etc).

16. I involve myself in social action and political groups even if there are no other Blacks involved.

17. I believe that Black people should learn to think and experience life in ways which are similar to White people.

18. I believe that the world should be interpreted from a Black perspective.

19. I have changed my style of life to fit my beliefs about Black people.

20. I feel excitement and joy in Black surroundings.

21. I believe that Black people came from a strange, dark, and uncivilized continent.

22. People, regardless of their race, have strengths and limitations.

23. I find myself reading a lot of Black literature and thinking about being Black.

24. I feel guilty and/or anxious about some of the things I believe about Black people.

25. I believe that a Black person’s most effective weapon for solving problems is to become part of the White person’s world.

26. I speak my mind regardless of the consequences (e.g. being kicked out of school, being imprisoned, being exposed to danger).

27. I believe that everything Black is good, and consequently, I limit myself to Black activities.

28. I am determined to find my Black identity.

29. I believe that White people are intellectually superior to Blacks.

30. I believe that because I am Black I have many strengths.

31. I feel that Black people do not have as much to be proud of as White people do.

32. Most Blacks I know are failures.

33. I believe that White people should feel guilty about the way they have treated Blacks in the past.
34. White People can’t be trusted.

35. In today’s society if Black people don’t achieve, they have only themselves to blame.

36. The most important thing about me is that I am Black.

37. Being Black just feels natural to me.

38. Other Black people have trouble accepting me because my life experiences have been so different from their experiences.

39. Black people who have any White people’s blood should feel ashamed of it.

40. Sometimes, I wish I belonged to the White race.

41. The people I respect most are White.

42. A person’s race usually is not important to me.

43. I feel anxious when White people compare me to other members of my race.

44. I can’t feel comfortable with either Black people or White people.

45. A person’s race has little to do with whether or not he/she is a good person.

46. When I am with Black people, I pretend to enjoy the things they enjoy.

47. When a stranger who is Black does something embarrassing in public, I get embarrassed.

48. I believe that a Black person can be close friends with a White person.

49. I am satisfied with myself.

50. I have a positive attitude about myself because I am Black.