

AN ABSTRACT OF THE THESIS OF

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A disproportionate amount of HIV/AIDS cases each year occur among African Americans. The purpose of this study was to review the numerous studies on HIV/AIDS conspiracy beliefs and their effects into one document. This research was done using research databases to identify peer-reviewed journal articles on HIV/AIDS conspiracy beliefs, and then reviewing and critiquing them. A review of the current studies shows that persons holding conspiracy beliefs are found to get more frequent HIV tests. The effect of conspiracy beliefs on treatment adherence is unclear given the current studies. Studies have found that HIV/AIDS conspiracy beliefs have a negative association with condom use. Historical events, such as the Tuskegee syphilis experiment, segregation of hospitals, the eugenics movement, and the case of Henrietta Lacks, provide a potential explanation for where the sense of distrust may have stemmed from. A review of the current body of knowledge revealed gaps in the absence of random samples, studies focusing on rural populations, studies focusing on women with HIV, and studies that involve people who have not been tested for HIV. Currently, no other compilation and critique of studies of this kind have been located on the subject of HIV/AIDS conspiracy theories and their effect on African Americans.

Key Words: HIV/AIDS, Conspiracy Beliefs, Medical Mistrust, African Americans

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A Critique of Studies on the Effect of HIV/AIDS Conspiracy Beliefs on African

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I understand that my project will become part of the permanent collection of Oregon State University, University Honors College. My signature below authorizes release of my project to any reader upon request.

Erica J. Puopolo, Author

This thesis is dedicated to my Mother, Christina C. Puopolo, and my Father, Richard S. Puopolo, for teaching me that with intelligence, hard work, and passion, there is no dream that is unattainable.

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I. Introduction

“Affirmative action was designed to keep women and minorities in competition with each other to distract us while white dudes inject AIDS into our chicken nuggets” (Glover, 2006). Although this quote from the popular American sitcom “30 Rock” may be seen as humorous, there are conspiracy theories in nearly every aspect of society (McCraffrey, 2012), and the HIV/AIDS pandemic is no exception (Alcamo, 2002). Before Acquired Immune Deficiency Syndrome (AIDS) was referred to as such, it was called GRID, or Gay Related Immune Deficiency (Alcamo, 2002). In America the disease has been closely connected to male homosexual minorities, but other minorities have been heavily affected as well. This thesis outlines the historical context for this distrust in the government and the healthcare system. It also provides an assessment on the current body of knowledge on the effect of HIV/AIDS conspiracy beliefs on African Americans.

African Americans comprise a disproportionately high number of new HIV infections in the United States. According to data collected in 2009 by the Centers for Disease Control and Prevention (CDC), African Americans comprised 14% of the US population but accounted for 44% of all new HIV infections (Centers for Disease Control and Prevention, 2012). The CDC estimated that the rate of new HIV infection for Black men in 2007 was more than six and a half times higher than in White men (Centers for Disease Control and Prevention, 2012). When one particular population is affected by a disease or condition more than other populations, it is imperative to analyze factors that could be contributing to this higher rate of infection.

A conspiracy belief is defined as “a theory that explains an event or set of circumstances as the result of a secret plot by usually powerful conspirators” (“Conspiracy Theory”). Conspiracy Theories in American History provides a slightly different definition:

At the most basic level, a conspiracy theory blames the current, undesirable state of affairs on a concerted conspiracy by a secret group. It is in effect an interpretation of history that claims that things aren't always what they seem, and that things haven't just tumbled out by coincidence in the normal, more-or-less random fashion, but they have only gotten like this because someone with evil intentions planned it this way (Knight, 2003).

Examples of HIV/AIDS related conspiracy beliefs are: 1) A lot of information about AIDS is being held back from the public, 2) HIV is a man-made virus, 3) There is a cure for AIDS, but it is being withheld from the poor, 4) The medicine used to treat HIV causes people to get AIDS, 5) HIV was created and spread by the CIA, 6) AIDS is a form of genocide against blacks, 7) The medicine that doctors prescribe to treat HIV is poison, 8) AIDS was created by the government to control the black population, 9) Doctors put HIV into condoms, 10) People who take the new medicines for HIV are human guinea pigs for the government, and 11) AIDS was produced in a government laboratory (Bogart & Thorburn, 2005). Other studies have used other conspiracy beliefs including “AIDS is an agent of genocide created by the U.S. government to kill off minority populations,” which was used in Ross, Essein, and Torres' study (2006). In general these studies conduct and assess conspiracy beliefs examined in HIV/AIDS research are beliefs

regarding the government, the origin of HIV, HIV as an agent of genocide, the withholding of information, treatment related beliefs, or a mixture of these.

This thesis will review and critique the current studies on HIV/AIDS conspiracy beliefs held by African Americans and their association with views toward HIV testing, treatment adherence, and condom usage. The objective is to examine the historical context that contributed to modern day conspiracy theories, and then review, synthesize, and critique the current body of knowledge on the effect of those conspiracy beliefs on African Americans. The purpose of this is to compile the information available so the reader can understand the effects of conspiracy beliefs of African Americans in one concise paper, and also read a critique on the presented studies. Suggestions for further research will also be provided based on the critique of the current studies. To begin, the methods used in the completion of this thesis will be outlined. A brief review of the historical context will then provide background on potential sources for conspiracy beliefs.

II. Methods

This thesis began with a compilation of peer-reviewed articles identified on research databases including, but not limited to: Journal Storage, Medline, and Google Scholar. More studies were then found by searching through the references of the first set of articles. Once relevant studies were located, they were sorted into topics and reviewed. The studies were then synthesized and critiqued. A literature search was then conducted on the historical context that has contributed to conspiracy beliefs and an analysis and critique were conducted of the overall body of knowledge.

III. Historical Context

Evidence indicates that conspiracy beliefs are endorsed by large percentages of the African American population (Clark, Mayben, Hartman, & Kallen, 2008). It is important in a pandemic as large and socially complex as HIV/AIDS to examine what the possible causes are for any factors that may be contributing to the continuation and spread of the disease, as well as what factors affect those who have already been infected in terms of treatment. Because conspiracy beliefs held by African Americans appear to have an association with sexual behaviors and attitudes toward condoms (Bogart & Bird, 2003), they may be a contributing factor in the spread of the disease. Evidence also indicates that conspiracy beliefs may be correlated with lower treatment adherence (Bogart, Wagner, Galvan & Banks, 2010). Therefore, it is important to analyze the origins of these beliefs.

The basis of any conspiracy theory is a sense of distrust. From a study of 1,200 community residents: “38.7 percent of African Americans and 40.5 percent of Caucasians stated that they were aware of the Federal regulations for human subjects protection... less than 50 percent of African Americans believed that scientists follow these regulations in contrast to almost 80 percent of Caucasian respondents... only 43.2 percent of African Americans perceived that African Americans receive the same quality of health care as Caucasians” (National Institute of Health, 2003). These data suggest that ethnic differences in trust exist. This is part of a larger historical context including the Tuskegee syphilis experiment, segregation of Blacks in the health care system, eugenics sterilization incidents, and the case of Henrietta Lacks.

In 1932, the Public Health Service, working with the Tuskegee Institute, began a study to record the natural progression of syphilis in hopes of justifying treatment programs for African Americans (Centers for Disease Control and Prevention, 2011). “Tuskegee study of Untreated Syphilis in the Negro Male” was the original title of the study (Centers for Disease Control and Prevention, 2011). This study involved 600 black men, 399 who were already infected with syphilis, and 201 who were not. The patients were initially told they were being treated for “bad blood,” a term used to describe a broader spectrum of ailments including syphilis, anemia, and fatigue (Centers for Disease Control and Prevention, 2011). In exchange for participating in the study, the men were given free medical exams, free meals, and burial insurance. In 1947, the use of penicillin as a cure for syphilis became widespread; the men in the study, however, were not offered this cure. The patients had agreed to be seen and treated, but there was little to no evidence that any of the patients were aware of the study or its purpose (Centers for Disease Control and Prevention, 2011). The syphilis study at Tuskegee was an ethically flawed, racist, and scientifically unsound study of 399 syphilitic African American male sharecroppers in Macon County, Alabama, who were followed by USPHS researchers for 40 years (or until their deaths). The public became aware of the story of the United States Public Health Service (USPHS) syphilis study at Tuskegee when the *New York Times* headlined the story titled, “Syphilis Victims in U.S. Study Went Untreated for 40 Years” (Heller, 1972). Bad Blood, a book by James Jones, published in 1981, outlined the entire story of the Tuskegee study. (Jones, 1981)

The Tuskegee syphilis experiment has gone down in history as one of the most infamous studies ever performed on human subjects. During the study, 28 men died

directly of syphilis, 100 had died of related complications, 40 of their wives had been infected, and 19 of the patients' children had been born with congenital syphilis (Williams & Williams, 2011). It has been criticized for breaching the Nuremberg Code (Appendix A), which was ignored by the PHS physicians/ biomedical scientists who conducted the study (Williams & Williams, 2011). The Nuremberg Code outlines the guidelines for acceptable protocol in human subjects research. Although the study was started fifteen years before the release of the Nuremberg Code, the study continued on for 25 years past the release of these ethical guidelines.

Tuskegee has been highly publicized since its end in 1972, and the greater effects on the general African American population are not necessarily known. It has been suggested that the study had a large effect upon African Americans and may have contributed to the overall sense of distrust of the government and health care system (Katz, 2011) that may be a basis for conspiracy beliefs. R. L'Heureux Lewis, PhD, assistant professor in the Department of Sociology and Black Studies Program at the City University of New York stated, in regards to Tuskegee and its effect on the African American race,

The role of racial conspiracy will continue to affect African Americans as we remember and imagine the past while experiencing the present. Contextualizing past atrocities, such as providing accurate information about the Tuskegee syphilis study, is still not enough given the current environment of racial paranoia. With more information like the Henrietta Lacks story and the sterilization of Puerto Rican women coming forward about communities of color, more fodder for concern is piling (as cited in Katz, 2011).

This quote by Lewis shows that the distrust of the government is rooted in a paranoia brought on by both past instances and current circumstances.

Another potential historical factor in medical distrust is the difference in treatment of Blacks in American hospitals until the end of the 21st century. In 1963, the U.S. Commission on Civil Rights published its findings on bias in hospitals based on race (Rice & Jones, 1994). The report was based on public hearings, staff field studies, reports of state of civil rights advisory boards, and a mail survey of 398 hospitals in 34 states (Rice & Jones, 1994). Approximately 55% of the hospitals responded to the survey, a total of 64 hospitals responded from Southern states. The Commission found that 60 hospitals had policies of exclusion or segregation, of these 60 hospitals 36 hospitals received Hill-Burton grants, and 3 were funded under the separate-but-equal provision (Rice & Jones, 1994). The other 33 hospitals, located in 14 Southern and border states, practiced separate living accommodations (Rice & Jones, 1994). Work was also done to narrow down information on specific cities. In Memphis, Tennessee, three large, private, church affiliated facilities with a total of 2,082 beds did not admit Blacks. A 128-bed, city owned hospital was the only general hospital available to Black patients. In Nashville, the only hospital facility available to Blacks was a 30-bed facility. Blacks were not admitted to any of the other four general hospitals (two church-affiliated) in the city. Another hospital, which had received a \$2 million Hill-Burton grant, kept separate facilities and a separate ward for Black adults (Rice & Jones, 1994). Similarly, in the local city hospital of Nashville, which received local public funds, a wing of only 28 beds was reserved for Black patients. The survey found many more examples of segregation and exclusion, including hospitals in Kansas City, Charleston, and Greensboro (Rice & Jones, 1994).

There was undoubtedly a lower standard for how Blacks were treated in hospitals, whether it is smaller hospitals, less funding, fewer doctors, or just the stigma of being separated to a different ward because of the color of their skin. This may have had even more of an impact upon views of the health care system than Tuskegee did because so many people were affected by the segregation and difference in treatment (Rice & Jones, 1994).

The eugenics movement of the United States began in the late 19th century and extended into the late 21st century. During this time, basing their work on a mix of scientific and pseudoscientific studies, American Mendelian eugenicists pursued policies of immigration restriction, segregation, and eugenic mating (Selden, 1999). American eugenicists focused on heredity as the primary agent for bringing about social change. They began to look at desirable and undesirable qualities. Charles Benedict Davenport was a prime factor in the organization of American eugenics; he combined his Mendelian views with strong beliefs in racial differences. He linked skin color to moral and mental qualities. “So far as skin color goes,” he explained to his readers, “mulattos with light skin pigmentation are truly as white as their great-grandparent and it is conceivable that they have mental and moral qualities as good and typically Caucasian as he had” (Selden, 1999). In 1913, Davenport published *State laws Limiting Marriage Selection in Light of Eugenics*. In it, he lists undesirable characteristics of Black Americans, including:

A strong sex instinct, without corresponding self-control; a lack of appreciation for property distinction (a capacity for which an African origin would hardly have contributed); a certain lack of genuineness- a tendency to pass off clever veneer for the real thing, due to inability of unwillingness to master fundamentals; and a

premature cessation of intellectual development (Selden, 1999).

The *Eugenical News* made notions of the differential worth of races, the idealization of the Nordic, and hailed the idea of state-sponsored sterilizations. This eugenics movement may have contributed to overall sense of distrust of the government and healthcare system because it was an example of racial ranking and mistreatment based on “scientific” evidence.

For example, during the 1960s, at a small sixty-three bed facility, the Fauquier County Hospital in rural Virginia offered contraceptive pills to women who could not afford them (Dowbiggin, 2008). Women who had had three or more children were offered a free tubal ligation and taught about sterilization. By 1963, of two hundred and three medically “poor” patients, sixty-three had been sterilized. About two-thirds of these sterilized patients were African American (Dowbiggin, 2008). There was an uproar from the public and from journalists who very much wondered how “voluntary” these sterilizations were. Catholic and African American journalists accused Fauquier staff of treating blacks like “second-class citizens” (Dowbiggin, 2008). In 1965, the director of the Broward County Health Department in Florida attempted to pass a sterilization plan that would sterilize the poor of Broward County (Dowbiggin, 2008). Coincidentally, the poor of these counties were overwhelmingly African American. Black opposition to family planning programs emerged quite swiftly. For example, in the 1960s, Malcolm X announced that family planning proponents targeted the “colored nations” of the world (Dowbiggin, 2008). Some black militants argued that, “birth control is just a plot, just as segregation was a plot to keep blacks down” (Dowbiggin, 2008). These quotes show evidence of public distrust beginning as early as the 1960s.

Low income and other minority populations were targeted by the eugenics movement (Dowbiggin, 2008). No case highlights this more than the case of Minnie Lee Relf, age twelve, and Mary Alice Relf, age fourteen (Dowbiggin, 2008). Both were young African American girls enrolled in an antipoverty program administered by the U.S. Department of Health, Education, and Welfare. On June 13, 1973, nurses came and retrieved Minnie Lee, Mary Alice, and their mother and brought them to the local clinic (Dowbiggin, 2008). It was there that Mrs. Relf, an illiterate mother of four on welfare, signed a consent form that she believed was for a birth control shot that the girls had received previously. The girls were operated on the next day and Minnie Lee was sterilized (Mary Alice was operated on, but not sterilized). Mrs. Relf insisted that she had not been informed that the consent form she signed was actually for a tubal ligation. Minnie Lee was one of over 16,000 females sterilized at clinics around the country in 1973. By the end of the movement, approximately 65,000 women had been sterilized (Dowbiggin, 2008). To those who know about the eugenics movement, there is no doubt that it would've contributed to a sense of distrust.

The sterilization cases were often masked by the “fight against poverty” (Lombardo, 2011). The Aid to Dependent Children Program (Lombardo, 2011) reported that, nationwide, the percentage of welfare recipients who were African American rose from 31 percent in 1950 to 48 percent in 1961. Similarly, the proportion of African Americans sterilized under the North Carolina Eugenics Board rose from 23 percent in the 1930s and 40s to 59 percent between 1958 and 1960 (Lombardo, 2011). Sterilizations both voluntary and involuntary swept across the nation, not only for African Americans but also for other poverty stricken women, or women deemed “unfit” (Selden, 1999). The

cultural implications of the eugenics movement extended past the end of the movement (Lombardo, 2011). Any woman entering a hospital in order to deliver a child, who ends up being unknowingly sterilized without her consent, would undoubtedly be left with no trust of the healthcare system. This mistrust, when included in historical context, could have played a major role in what eventually led to conspiracy beliefs.

A specific case of medical mistreatment is the case of Henrietta Lacks. Henrietta Lacks was an African American woman from Southern Virginia who developed cervical cancer at the age of 30 years old. While Henrietta was admitted into the John Hopkins hospital for a growth she felt on her cervix, a doctor removed a piece of her tumor on February 8th, 1951, without her consent (Skloot, 2010). The cells were then cultured and have been grown in laboratories ever since. The cells have been used for extensive amounts of scientific research. HeLa cells were used in the development of the polio vaccine, they are used for cancer research and research on viruses, they have been into space, and they led to the discovery of the number of human chromosomes. (Skloot, 2010) Rachel Skloot published a book in 2010 titled, The Immortal Life of Henrietta Lacks, outlining the story of Henrietta Lacks and also the struggles that her family has faced since the time of her death. Despite the fact that HeLa cells, the coined names of Henrietta's cells, have raised an, "incalculable amount of money," according to Skloot (Lane, 2010), her remaining family members are not even able to afford health insurance. Her middle child, Sonny, is said to be over 100,000 dollars in debt due to bypass surgery (Lane, 2010). Because the case of Henrietta Lacks is very specific and really only affected her and her family, it probably has not had as much of a societal impact as Tuskegee, racial segregation in hospitals, and involuntary sterilizations. It could be

viewed by African Americans, however, as another example of mistreatment. Henrietta's cells gave researchers an immortal line for research, her cells have lead the way toward new scientific advancements, and yet her family cannot even afford health care (Skloot, 2010).

Many conspiracy theories can arise from a sense of distrust: a distrust of the government and healthcare system that stems from medical mistreatment such as the examples noted above. Tuskegee, segregation, sterilization, and the case of Henrietta Lacks are all examples of how African Americans have been mistreated by the healthcare system. These examples show how African Americans have been taken advantage of (e.g., used for research unknowingly and had medical procedures done against their wills) and how these incidents are potential roots from which conspiracy beliefs stem.

The following sections will outline the assess the studies on the effects of conspiracy beliefs on HIV Testing, treatment adherence, and condom use.

IV. HIV Testing

The diagnosis of HIV infection close to time of transmission is beneficial for numerous reasons, including an earlier initiation of anti-retroviral treatment and the potential reduction in HIV transmission behaviors (Alcamo, 2002). Testing is valuable because it encourages entry into medical care earlier during the progress of the disease. Infected persons can receive highly active antiretroviral therapy (HAART) using azidothymidine (AZT) and protease inhibitors (Alcamo, 2002), which has been shown to improve the duration of life and reduce the damage to the immune system, thereby delaying the onset of AIDS (U.S. Department of Health and Human Services, 2011). The

goals of anti-retroviral treatments are to reduce HIV-associated morbidity and prolong the duration and quality of survival, restore and preserve immunologic function, maximally and durably suppress viral load, and prevent HIV transmission. (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2012) For individuals who are infected with HIV but do not know their HIV status, which the NIH estimates to be approximately one fifth of the million Americans currently living with HIV (U.S. Department of Health and Human Services, 2011), testing programs can link the individuals to healthcare programs and assist them in adhering to treatment regimens and encourage them to adopt risk-reducing behaviors (Alcamo, 2002). Because African Americans have one of the highest rates of infection of any population in America (CDC, 2012), it is important to analyze factors that may affect these numbers. Understanding the attitudes of African Americans to HIV and HIV testing is potentially important for developing culturally sensitive policy and interventions to reduce the spread of HIV (Bohnert & Latkin, 2009).

A study by Clark, Mayben, Hartman, and Kallen, (2008) titled “Conspiracy beliefs about HIV infection are common but not associated with delayed diagnosis or adherence to care” showed that patients who endorsed one or more conspiracy belief had a higher CD4 T-cell count at diagnosis and higher CD4 T-cell counts at the time of the study. The study suggests that higher CD4 T-cell counts at the time of diagnosis correlate with more frequent HIV testing because HIV attacks and destroys the T-cells of the immune system and therefore the patient will have higher T-cell rates closer to their time of infection. Therefore, more frequent testing will be directly correlated with higher T-cell counts at time of study. This study was not population specific and was based upon a

purposive sample of HIV positive patients from publically funded facilities in Houston, Texas.

The patients were asked questions about the following five conspiracy beliefs: 1) HIV was released on purpose by the government, 2) the government has a cure for HIV but will not release it, 3) the government has a vaccine to prevent HIV infection but will not release it, 4) the drug companies have a cure for HIV but will not release it, 5) the drug companies have a vaccine to prevent HIV infection but will not release it. Potential predictors of conspiracy beliefs in the study were evaluated and included demographic characteristics, education, employment status, income, insurance, homelessness, and HIV risk factor.

CD4 cell counts were tested and recorded at diagnosis. CD4 cell count at diagnosis and current CD4 cell count were ascertained from medical record review. There were a total of 113 patients in the final study. 73% of African Americans in the study endorsed at least one conspiracy belief, which is significantly higher than other ethnic groups within the study (Clark, Mayben, Hartman, & Kallen, 2008). There is significant association (p-values of .03 and .04) between belief in at least one conspiracy theory and higher rates of CD4 T-cells. The researchers in this study concluded that they believe that patients' views toward their own health care needs overshadowed their views toward the government.

One of the limitations of the Clark, Mayben, Hartmann, and Kallen (2008) study stems from the fact that because the participants are coming from publically funded facilities, it excludes patients who have not been HIV tested and are therefore are not receiving treatments. These are potentially the people with the highest level or most

extreme beliefs in conspiracy theories. It also excludes any participants who may have been tested for HIV but who were not engaged in treatment, which may also include patients with high levels of distrust toward the health care system. Patients were excluded if they were deemed too sick to participate, which may also exclude some of the patients that were diagnosed with HIV later in the course of infection, potentially indicating less frequent testing patterns. Also, because the data came from a purposive sample and the participants were referred by physicians, nurses, and social workers, the reader must be careful when applying these findings to the greater population. The study uses data from multiple ethnic groups with 53% of participants identifying themselves as black, 32% as white, 15% as another race or more than one race, and 27% identified themselves as Hispanic (Clark, Mayben, Hartman, & Kallen, 2008). This means that although the study is applicable to a wider range of ethnic groups, it is not necessarily as relevant to apply these findings to African Americans specifically.

In 2009, Bohnert and Latkin published a study titled, “HIV testing and conspiracy beliefs regarding the origins of HIV among African Americans,” in order to expand upon the research by Clark and colleagues regarding the relationship between conspiracy theory beliefs and HIV testing patterns of African Americans (Bohnert & Latkin, 2009). The study took place in Baltimore, Maryland, and participants were asked questions in face-to-face interviews. The 1546 African American participants of the study were largely drug users, as 72% reported using heroin and/or cocaine in the prior 6 months, 62% reported injecting drugs at least once, and 89% had a lifetime history of heroin and/or cocaine use (Bohnert & Latkin, 2009). The African American sample was 61%

male, and 19% reported being HIV-seropositive. Only 7% reported ever having been married, but 61% currently had a main partner (Bohnert & Latkin, 2009).

Participants were asked if they agreed with the statements “AIDS was started by an experiment that went wrong” and “AIDS was created to kill blacks and poor folks” on a four-point scale, with the choices “strongly agree,” “agree,” “disagree,” and “strongly disagree,” where a lower score indicated greater agreement. Lifetime history of HIV testing was assessed via the question “Have you ever been tested for HIV?” Chi-squared tests were then performed on the data. Among participants, 6.8% reported never having had an HIV test. The distribution of the responses to the statement “AIDS was started by an experiment that went wrong” was as follows: 24.8% strongly agreed, 19.7% agreed, 17.9% disagreed, and 37.6% strongly disagreed. For the statement “AIDS was created to kill blacks and poor folks,” 11.4% strongly agreed, 13.2% agreed, 14.3% disagreed, and 61.2% strongly disagreed. In total, 22.5% of participants had a sum score on the conspiracy beliefs items that was less than five, indicating agreement with the conspiracy beliefs, on average (Bohnert & Latkin, 2009). Of those who agreed with conspiracy beliefs on average, only 4.0% reported never having an HIV test, while 7.7% of those who did not endorse conspiracy beliefs on average reported never having an HIV test (Bohnert & Latkin, 2009).

The study has reported limitations, including that the data for HIV testing was self-reported. It is not known whether the participants had actually received or understood the results of their HIV tests. It also does not give any data for frequency of HIV tests, only whether or not the patient has been tested at any point in their life. A testing rate of 93% is reported as high even for a population that is considered to be at

high risk. In a sample of inner city African Americans in Chicago, approximately 75% reported having ever had an HIV test (Djokic, Englund, Daum, Martin, Dozier, & Potts, 2009), and in a national sample 67.1% of those with a lifetime risk factor (including injection drug use or sex with an injection drug user) reported ever having an HIV test (Ostermann, Kumar, Pence & Whetten, 2007). The high rate of testing suggests that it may be difficult to generalize the findings to apply to the greater population, as the relationship of testing with beliefs and other covariates may be very different for populations with lower rates of testing (Bohnert & Latkin, 2009). Other limitations of this study include the fact that there were no women included, and also that the study is based on a purposive sample from a large city. Therefore the data may not be applicable toward rural populations and may even differ substantially from rates of HIV testing in large cities in different parts of the country.

At this time there has not been extensive research on the effect of conspiracy beliefs on the HIV testing patterns of African Americans based on a randomly selected nationwide sample. It would be beneficial to pursue this to determine whether or not conspiracy beliefs, especially views on the more extreme side of the spectrum, do indeed have an effect on the testing patterns of African Americans, or whether the above studies are correct on a broader scale and conspiracy beliefs do not have an adverse effect on testing patterns. So far, the studies have all focused on large metropolitan cities. The views and patterns of rural populations, therefore, are largely absent from the body of scientific knowledge. People with HIV who have not had an HIV test are also not represented in these studies. Although it would be logistically difficult, if not impossible, to design a study focusing on this population due to fact that a person would have to get

tested in order for the researcher to know they had HIV. The findings may be drastically different than the findings pertaining to African Americans who have been tested.

Overall, the two studies above suggest that HIV conspiracy beliefs correlate to higher rates of testing, but it would be beneficial to test this claim further by looking at more locations and different populations, and by performing a study involving a random sample rather than a purposive sample.

V. Treatment Adherence

Compared to their White counterparts, African Americans with HIV show lower rates of antiretroviral treatment utilization, adherence to therapeutic regimes, and reduced survival times (Bogart, Wagner, Galvan & Banks, 2010). A 2008 study by Clark, Mayben, Hartmann, and Kallen found that although 73% of African Americans endorsed one or more conspiracy belief and had higher CD4 counts at the time of the study, there did not appear to be a statistically significant difference between participants who endorsed conspiracy theories and those who did not, in the rates of treatment adherence throughout the study (Clark, Mayben, Hartman, & Kallen, 2008). There is currently no conclusion on whether conspiracy beliefs have been shown to have an effect on treatment adherence and care.

In a 2010 study by Bogart, Wagner, Galvan, and Banks, 214 African American men with HIV were surveyed on their belief in two different types of conspiracy theories, including genocide-related theories and treatment-mistrust theories (Bogart, Wagner, Galvan & Banks, 2010). The participants were recruited using fliers disseminated and posted by staff at three HIV social service agencies and an HIV medical clinic (Bogart,

Wagner, Galvan & Banks, 2010). Their treatment adherence was then monitored electronically for one month; at that time a final survey was given. 177 participated in the entire study, which includes completion of the pre-survey assessment as well as the one-month follow up assessment. Bivariate statistical analyses were performed, and it was determined that stronger belief in treatment-related conspiracies were associated with a lower likelihood of the patients adhering to an “optimal treatment adherence” of over 95% of doses taken (Bogart, Wagner, Galvan & Banks, 2010).

One of the limitations of this study is that it involved a purposive sample and therefore the data were not necessarily representative of African American men with HIV as a whole. The men had to volunteer for the study, which may exclude data from African American men with extreme conspiracy beliefs. It has been observed that African Americans who hold conspiracy beliefs are more likely to report fear in participating in biomedical studies (Katz, Russell, Kegeles, & Kressin, 2006). This may also contribute to fear in participating in government-funded treatments as well. Men involved in the study were already engaged in antiretroviral treatment, which limits the generalizability to individuals who have been tested for HIV, have been admitted into care, have a healthcare provider, and have chosen to accept treatment. The study states that people exhibiting the strongest levels of conspiracy beliefs may not be well represented in the sample because they may have been too mistrustful of the health care system to advance through the multiple stages of the HIV care continuum (Bogart, Wagner, Galvan & Banks, 2010). There are a few areas of this study that could be expanded on in further research that the authors did not include. The study does not include any information on the treatment adherence of females who are HIV positive. It may be more beneficial in

the future to conduct a study using people who have tested positive for HIV, but whom are not currently enrolled in a treatment adherence. They could answer survey questions on their views toward conspiracy beliefs and then perhaps contrast the findings with a study consisting of patients who are currently undergoing treatment in a facility.

The study by Clark, Mayben, Hartman, and Kallen (2008) titled “Conspiracy beliefs about HIV infection are common but not associated with delayed diagnosis or adherence to care,” showed that patients with a belief in one or more conspiracy theories had higher CD4 T-cell counts at the time when the study was performed. The study is outlined in the HIV Testing section on pages 12 and 13. Compared to persons without conspiracy beliefs, persons with conspiracy beliefs had higher CD4 cell counts at diagnosis of HIV infection and higher current CD4 cell counts, but similar use of HAART and adherence to HAART, similar retention in medical care, and similar overall health and quality of life. Again, the researchers in this study concluded that they believe that a patient’s view toward the government and conspiracy theories involving the government do not have an effect on their views toward their need for their own health care (Clark, Mayben, Hartman, & Kallen, 2008).

The limitations of this study are discussed under the HIV Testing section and include the sample being a purposive sample from a publically funded facility, therefore excluding people who have not been tested, or have been tested but have chosen not to participate in treatments. It also involves data from more than just the African American population; this may limit the relevancy of the data when applied to only African Americans.

The information currently available on HIV conspiracy beliefs and their effect on treatment adherence is quite limited and the results of the current studies are contradictory. Bogart, Wagner, Galvan and Banks (2010) found that conspiracy beliefs do indeed have a negative impact on the participants of the study, including lower quality of life and lower survival rates indicating lower treatment adherence rates. Clark, Mayben, Hartman, and Kallen (2008), however, did not find statistically significant difference in treatment adherence between participants who did versus those who did not hold conspiracy beliefs. It would be beneficial for more studies to be conducted in order to see whether conspiracy beliefs have an effect on treatment adherence. Anti-retroviral treatments are an integral part of slowing down the progression of HIV into AIDS (Alcamo, 2002), and it is therefore important to identify factors that have an impact on rates of adherence.

VI. Condom Use

Among all ethnic groups of both genders, the population with the highest diagnosis rates of HIV and AIDS are African American men (CDC, 2012). Condoms are an integral part of reducing the risk of contracting HIV, as well as other sexually transmitted diseases (Alcamo, 2002). It has been hypothesized that HIV/AIDS conspiracy beliefs and condom attitudes may be correlated among African Americans because individuals who lack trust in the information about HIV/AIDS provided by the US government and public health system also may not trust the information provided regarding condoms (Bogart & Thorburn, 2005).

A 2005 study by Bogart and Thorburn was conducted via anonymous telephone survey between September 2002 and March 2003. Phone numbers were generated by a random digit dial system targeted at areas in the contiguous United States with approximate densities of 27% or greater based on US Census data (Bogart & Thorburn, 2005). Participants were chosen if their age was between 15 and 44 years old, they identified as “Black or African American,” and if they were the member of the household who had last had a birthday. A total of 500 houses successfully completed the telephone interview. Between 1% and 60% of the participants endorsed conspiracy beliefs regarding HIV/AIDS. The survey found that there were few participants who endorsed the most extreme conspiracy beliefs such as, “Doctors put HIV in condoms.” The largest majority of beliefs were regarding the government withholding information or a cure for AIDS. The study found that a significantly greater percentage of men endorsed conspiracy beliefs than did women. ($P < 0.01$). Although HIV/AIDS conspiracy beliefs and condom attitudes were not correlated among women, for men HIV/AIDS conspiracy beliefs were significantly associated with condom attitudes and condom use. The study found that men who held stronger HIV/AIDS conspiracy beliefs had more negative attitudes toward condoms and were less likely to use condoms consistently. Overall, the study suggested that HIV/AIDS conspiracy beliefs may potentially be a barrier to HIV prevention, particularly for Black men (Bogart & Thorburn, 2005).

Bogart and Thorburn’s (2005) study was conducted with a nationwide, random sample of African Americans via telephone. The results are, therefore, generalizable. A potential limitation may be that because the interviews were based solely on whether or not the participants accurately report their conspiracy beliefs, there is a possibility that

not all of the data received were accurate. This is counterbalanced by the fact that the surveys are anonymous and conducted over the phone, and therefore the participants should have felt no pressure or embarrassment that would cause them to lie or answer in any particular way. This study shows that conspiracy beliefs may indeed have a negative effect upon the actions of those who endorse them. To expand on this study, perhaps a project could be developed that focuses on African American men who are currently HIV positive and determine if there is a difference in how men with HIV are affected by HIV conspiracy beliefs in terms of sexual behaviors in comparison to this random sample of African American men. This may be important in determining a potential factor in the spread of the disease. If the men in this study who endorsed conspiracy beliefs have a more negative attitude toward condoms, then perhaps so do African American men with HIV making them more likely to spread the disease. This study would be nearly impossible to do via random sampling due to sheer numbers of contacts that would need to be made in order to reach a large enough sample size with such a specific group of the overall population.

During a six-month study in 2011 titled, “Longitudinal association of HIV conspiracy beliefs with sexual risk among black males living with HIV,” Bogart, Galvan, Wagner, and Klein measured the endorsement of HIV conspiracy beliefs three times and the frequency of condom use monthly among the study's participants. The participants of the study included 181 HIV-positive African American males. They were recruited using fliers at 3 HIV social service agencies and an HIV medical clinic in Los Angeles, CA. Participants were given a survey at the beginning of the study, assessing both sexual behaviors and HIV/AIDS conspiracy beliefs. Participants returned monthly to assess their

sexual behaviors since the previous survey, and at 6 months after baseline the survey reassessed conspiracy beliefs (Bogart, Galvan, Wagner, & Klein, 2011). The study indicated that greater belief in HIV conspiracies was significantly associated with a higher likelihood of reporting unprotected intercourse across all time points. On average, 54 percent of participants who endorsed conspiracies reported engaging in unprotected sex, while 39 percent who did not endorse conspiracies reported engaging in unprotected sex.

The Bogart, Galvan, Wagner, and Klein (2011) study was not random; therefore the findings are not necessarily applicable to the general population of all African American men with HIV. Although the Bogart and Thorburn (2005) study used random sampling from across the nation, the current study used only participants from Los Angeles, thereby excluding rural populations from the study, as well as other areas of the country. The study does, however, make a good extension to the Bogart and Thorburn (2005) study; the findings are congruent with the study, similarly finding that men with higher levels of conspiracy beliefs showed more negative attitudes toward condoms and less consistent condom usage. Finding a way to rebuild trust in the government and health care system and lower the rates of perceived conspiracy may lead to a lowering of HIV transmission. To expand on the current body of knowledge a study could also be conducted consisting of African American females with HIV, to see if their views differ from those of the general population of African American females.

VII. Critique of Current Body of Work/ Suggestions for further Research

A substantial portion of the African American population currently holds HIV/AIDS conspiracy beliefs (Clark, Mayben, Hartman, & Kallen, 2008). It would be

important to continue the search for the cause of these beliefs on a broader scale in order to determine whether the mistrust stems fully from a historical basis of medical mistreatments, or what amount is due to political and social circumstances of prejudices that African Americans may observe from both historical events and present day experiences. It is important to do this because patients should be able trust their healthcare providers, and if medical mistreatments are the reason for the patients' distrust then it would be beneficial to target developing programs that attempt to rebuild that sense of trust.

A weakness in current research is the lack of studies that focus around rural populations. Nearly all of the studies listed in this thesis were conducted in large cities, Chicago, Baltimore, Los Angeles, etc. It is understandable that these locations would be used because they have the highest concentration of people, and therefore it is easier and more convenient to reach a large enough sample size. Larger cities also tend to have higher rates of HIV ("United States statistics," 2011). A recommendation for further research would be to gather and compare the views of rural African Americans with the knowledge known about African Americans from urban areas.

It would also be beneficial to include more studies involving large, random sampling of people across the nation to see whether the results from the studies that consist of convenient or purposive samples are generalizable on a larger scale. The vast majority of the studies have been purposive samples, which makes sense because it truly is more convenient to run a study based on this type of sampling method. It is also assumedly more cost effective in general. However, without random sampling, the findings are not technically applicable to the greater population. Thus a purposive sample

conducted with African American males from a facility in Houston, Texas, is not necessarily generalizable to all African American males, or even all African American males from large cities, it may only be applicable to African American males from that specific facility in Houston, Texas. A purposive sample is not necessarily very useful to the overall body of knowledge, which is why it would be beneficial to complete more random samples either by phone or by some other mode of information retrieval.

Conducting a study that was able to test whether or not knowledge of the Tuskegee syphilis study is linked to greater mistrust in medical care would also be beneficial for the overall body of knowledge. It would be important to design a study in which the broader issue of mistrust is narrowed down from being reluctance to join medical studies or utilize health services to how the mistrust directly contributing to belief in HIV/AIDS conspiracy beliefs is affected by knowledge of historical examples of medical maltreatment. There is a large amount of information available on African Americans willingness to participate in medical experiments (Katz, 2010; LaVeist, Nickerson & Bowie, 2000) and whether history (specifically Tuskegee) has had contributed, whereas there is small amount of information about whether or not these historical events directly impact HIV/AIDS conspiracy beliefs.

Another point of weakness in the body of data is the ability for studies to reach people who may hold the largest amount of conspiracy beliefs. These people would most likely not be involved in any government health care and are therefore excluded by almost all of the studies with the exception of Bogart and Thorburn's (2005) study, in which participants were randomly contacted by telephone and it was, therefore, not necessary for these participants to be in contact with any kind of health care providers in

order to be contacted. It is difficult to make assumptions about data when there are possibly entire sections of afflicted populations unrepresented in the data sets. This is especially so when it is a group that may potentially have a large impact on the overall data.

These recommendations for further research are important because in a pandemic as large and complex as HIV/AIDS it is important to understand as many of the factors that may possibly lead to higher rates of disease. These studies become important when designing HIV/AIDS prevention and treatment programs, understanding more about each population and their beliefs makes it easier to determine the best place to start targeting with prevention and treatment programs.

VIII. Conclusion

From this thesis the reader has now been informed of existing HIV/AIDS conspiracy beliefs and has been informed on the possible roots of these conspiracy beliefs. The reader has been provided with a compilation of existing information of the effects of conspiracy beliefs on African Americans and has also been provided with a critique on each of the presented studies. A critique on the overall body of knowledge has also been presented, and recommendations have also been made for further research. Currently, no other compilation and critique of studies of this kind have been located on the subject of HIV/AIDS conspiracy theories and their effect on African Americans.

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Appendix A

National Institute of Health
Regulations and Ethical Guidelines

Directives for Human Experimentation

NUREMBERG CODE

1. The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonable to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment. The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.
2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.
3. The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problem under study that the anticipated results will justify the performance of the experiment.
4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.
5. No experiment should be conducted where there is an a priori reason to believe that death or disabling injury will occur; except, perhaps, in those experiments where the experimental physicians also serve as subjects.

6. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
7. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.
8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.
9. During the course of the experiment the human subject should be at liberty to bring the experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.
10. During the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the exercise of the good faith, superior skill and careful judgment required of him that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

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