

Medical Mistrust, Conspiracy Beliefs & HIV-Related Behavior Among African Americans

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Abstract

Health care promotion and disease prevention among African Americans has become a significant area of study due to the number of medical issues that disproportionately affect the Black community. HIV research, in particular, has received a great deal of attention due to the destructive cognitive behavioral and lifestyle components that are believed to promote the transmission of the virus. A long history of medical experimentation and abuses of African Americans has led to feelings of vulnerability, suspicion and mistrust towards institutions of medicine among the Black community. This paper explores literature surrounding these suspicions and points to historical events and possible triggers of medical mistrust. Also, this review highlights an irony within the African American community: these very conspiracy beliefs and feelings of medical mistrust may actually be leading to a series of maladaptive and self-destructive behaviors that may be stifling HIV treatment and prevention efforts within this population.

Introduction

Recently, increased attention has been given to the issue of medical mistrust as it may contribute to poor access to medical care and ethnic disparities in care. Research has indicated that medical mistrust among minorities, particularly African Americans, stemmed from various historical events, including the Tuskegee Syphilis Study. This non-therapeutic experiment, controversial in retrospect, was conducted between 1932 and 1972 and depicted medical research and social experimentation at its worse: rife with ethical violations and human rights abuses, by modern standards. Some believe that the study triggered much of the medical mistrust we see today in the African American community. Medical mistrust remains prevalent within this group and reestablishing trust within this community is essential to controlling health disparities. Disparities in health care have been shown by African American's lower life expectancy and higher death rates compared to other racial/gender groups. A glance at current HIV statistics, indicating the most rapid rate of transmission of HIV among African Americans, is yet another example of such disparity. This paper will review the literature on medical mistrust, its prevalence in the African American community and its relationship to HIV-related behaviors within the African American population.

This paper will also provide evidence for a possible link between medical mistrust and the spread of HIV, suggesting that addressing conspiracy theories directly among African American patients may be a key step in managing the transmission and treatment of this virulent infection.

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Cultural mistrust has been defined as a tendency to distrust Whites based upon a legacy of direct or vicarious exposure to racism or unfair treatment by Whites¹. Others have defined such mistrust as a “racism reaction²” that has evolved as a defensive mechanism. Medical mistrust is, consequently, the tendency to distrust institutions of medicine, including medical personnel and clinicians, who represent the dominant culture. As a result of past and present discrimination and racial persecution, various medical conspiracy theories have evolved, which serve to perpetuate medical and cultural mistrust. Unfortunately, these beliefs have led to a series of negative health-related behaviors within the African American community.

Review of Literature on Medical Mistrust

A conversation about today’s health care system represents more than a simple dialogue about current medical issues; rather, it revolves around the constant interplay of the economic, political, legal and social aspects of our community. As more advanced medical technology is used to effectively treat more illnesses, patients are, more than ever, having to put their health in the hands of health care providers. Consequently, trust has become one of the foundations upon which our health care system is built³. Given that the patient is often in a vulnerable position, at the mercy of the health care provider to do what is in their best interest, a sort of medical dependence and reliance is inevitably built.

Trust is, often, a precarious dynamic that is established over time between persons or parties, and researchers have pointed to various discriminatory events in history that may have triggered medical mistrust amongst minorities. In particular, the 1932-1972 Tuskegee Syphilis Study is frequently described as one of the most significant catalysts for medical mistrust that exists in medicine today⁴. This study served as an experiment to examine the natural progression of untreated syphilis among 600 African American men. After denying these male participants access to penicillin for years after the treatment became available, many developed the complications of the illness and died. Others unknowingly spread the disease to their wives and had children born with congenital syphilis. This experiment has been deemed “the most infamous biomedical research study in U.S. history”⁵ and has resulted in the establishment of many standards aimed at protecting human subjects involved in scientific experiments. Not only did this study lead to legal and policy-related reform but it has also left a trail of medical suspicion and mistrust over 80 years after the study first began.

Certain scholars question whether the Tuskegee Syphilis Study actually triggered medical mistrust, claiming that medical mistrust existed decades prior to the shocking revelations about the study⁶. Historical events such as the Henrietta Lacks case and medical experimentation on slaves show a legacy of medical abuse that predates Tuskegee⁷. In a detailed account of the years of experimentation inflicted upon African American subjects, Washington (2008) asserts that dangerous, involuntary and unethical experiments have been carried out on African American subjects since the eighteenth century⁸. In the oral tradition, common in African American culture, many of these accounts of medical and personal violation were passed down orally, from generation to generation. However, the evidence of medical abuse was seldom, if ever, acknowledged. The Tuskegee experiment was, therefore, the first, formal record of the exploitation of African American subjects in scientific research and it has, in a sense, become the face for medical abuse of African Americans.

To deny the long history of horrific experimentation that occurred prior to Tuskegee would be a gross historical and scientific oversight. While research has indicated that African Americans are more likely to be aware of the Tuskegee study than other races⁹, much of the information African Americans reported about the study was false¹⁰. Furthermore, research by Katz et al (2008) shows that, even for African Americans who were aware of the Tuskegee experiment, there was no direct connection between detailed knowledge of this experiment and medical mistrust⁵.

The presence of medical mistrust in the African American community, must, therefore, be due to broader historical events, personal experiences and a complex interplay of additional factors¹¹. These findings may help to explain why there is still a significant level of medical mistrust in the African American community despite the fact that many blacks have little to no awareness about the Tuskegee Study.

While disagreement persists regarding the historical trigger and ultimate cause of medical mistrust, researchers tend to agree that the Tuskegee Study certainly contributes to the negative history of scientific experimentation among African Americans¹¹. These negative attitudes continue to be reinforced by personal experiences of discrimination and injustice in the health care system today.

Prevalence of Medical Mistrust in African American Community

As a result of past discriminatory events in history as well as negative personal health care experiences, research by LaVeist (2000) has illustrated that African Americans, as a group, are significantly more suspicious of both private and governmental health care institutions¹². In a community-based sample, 70% of African Americans believed that the government was hiding information and not telling the truth about the HIV/AIDS epidemic¹³. As a result of these suspicions, African Americans often report less satisfaction with the medical care they receive. Similar research has indicated that Blacks are significantly less likely to trust their physicians and significantly more concerned about personal privacy and harmful experimentation within medical settings than their White counterparts¹⁴. These results have long-term implications for minority involvement in clinical research. In a qualitative study by Corbie-Smith et al. (1999) African Americans explicitly reported distrust for the medical community, and cited this as the main barrier to participation in clinical studies¹⁵. Similar findings have been reported in more current research¹⁶. The belief that medical institutions use African Americans as “guinea pigs” for scientific research was a prevalent notion in the past and it persists today¹⁷.

Despite findings showing that African Americans are significantly more likely to perceive racial inequality and report health care suspicions and generalized medical mistrust, it is interesting to note that, in the past, neither black nor white patients openly endorsed the existence of racism in the medical care system¹². These, seemingly, contradictory findings may suggest an unconscious level of perceived discrimination among African Americans in medical settings. The widespread effects of perceived discrimination in medical settings were highlighted in research by Casagrande et al. (2007). Negative discriminatory experiences were correlated with delays in seeking medical care as well as poorer immediate and long-term adherence to medical care recommendations¹⁸. These findings were independent of medical mistrust, suggesting that African American’s experiences with discrimination in health care settings may be an equally powerful predictor of health care attitudes and behaviors as actual measures of medical mistrust.

Research by Shelton et al. (2010) suggests that medical mistrust is exacerbated by negative discriminatory experiences. Awareness of historical events and lingering mistrust from the 1930s syphilis experiment manifests itself today in various forms including fewer physician visits, non-adherence to medical treatments and more negative health-related attitudes¹⁹. Specifically, African American men’s lower levels of health care involvement, including access to and engagement in routine health care, has been directly associated with medical mistrust¹⁹. These findings have major implications for health care promotion and disease prevention, particularly those diseases that disproportionately affect the Black community.

Relationships between Medical Mistrust and HIV Related Behavior

Both past and present research has indicated that HIV is spreading faster among African Americans than any other racial group²⁰.

Despite findings that rates of infection are on the decline²¹, African Americans continue to have a disproportionately high rate of HIV. Many have attributed this epidemic to the growing number of gay and bisexual Black men. Others have sited the “down under” culture of men sleeping with men. Research indicates that an estimated 50% of individuals living with HIV are unaware of their status²², and researchers have suggested that the “down under” culture may be a phenomenon that is perpetuated by African American males’ unawareness of the potential risk of their behavior. Other scholars assume a more retrospective view, claiming that various historical events, including the Tuskegee Syphilis, are historical markers in the HIV pandemic⁸. Proponents of this theory believe that a series of historical events triggered medical mistrust, resulting in various conspiracy theories regarding the virus. These beliefs have, in turn, led to a series of maladaptive behaviors on the part of African Americans that have stifled HIV prevention and treatment efforts.

Based on current research, there appears to be two distinct, and relatively widespread, HIV-related conspiracy theories that exist within the African American community. Although these conspiracy theories have also been found to exist in Latino, Asian and White populations, it is with significantly lower rates²³. The first theory, the genocidal conspiracy theory, revolves around notions that HIV is a manmade virus created and spread by the CIA and that the cure for HIV is being systematically withheld from the poor. Although this theory dates back to the 1980s, when the HIV/AIDS epidemic was first reported by the Centers for Disease Control (CDC), a national sample of African Americans in the U.S. indicated that nearly half of respondents somewhat or strongly endorsed the belief that HIV is a manmade virus²⁴. This is clear evidence that genocidal conspiracy theories persist today and may be more common among African Americans. The second is a treatment-related conspiracy theory, centered on beliefs that the new medications for HIV actually cause people to get AIDS and those taking these new medications are guinea pigs for the government²⁵.

Both genocidal and treatment-related conspiracy theories stem from an underlying mistrust of medical institutions, which propagate beliefs that the government, is trying to systematically wipe out the African American race. With these beliefs, many African Americans have become suspicious of any advice from medical institutions. This mindset has become particularly detrimental to African Americans with respect to HIV treatment and prevention and has led to a series of self-destructive behaviors within this racial group²⁶.

Mistrust/Conspiracy and Condom Use

The negative correlation between conspiracy beliefs and condom usage has been the focus of much research, as it poses serious concerns about HIV prevention. In a study by Ross et al. (2006) a significant correlation was found between African American males’ conspiracy theory beliefs and condom use, such that those who held conspiracy beliefs were less likely to use condoms²³. It is interesting to note that a significant negative correlation was only present for African American males in this study and did not exist for any other racial/gender group. Similar findings were reported in a longitudinal study by Bogart et al (2011): presence of conspiracy beliefs was a significant predictor of unprotected intercourse with HIV-positive or unknown serostatus partners²⁵. Many believe that African American male’s resistance to condom use is fueled by genocidal beliefs about HIV. Research suggests that those who endorse beliefs that the government is playing an active role in facilitating the HIV/AIDS epidemic are more suspicious of government funded efforts and public health messages to promote condom use.

Mistrust/Conspiracy and HIV Testing

Medical mistrust and genocidal conspiracy theories impede HIV prevention efforts in the African American community with respect to HIV testing.

Given a fundamental mistrust for government institutions and systems promoting HIV prevention, detection and treatment, many African Americans are avoiding getting tested at medical hospitals and clinics. Particularly for Black men who have sex with men (MSM), endorsing conspiracy beliefs was significantly correlated with not having been tested for HIV²⁷. Given recent findings that Black MSM have higher rates of undetected HIV infections, and the blurring divide between married heterosexual men and married MSM, there is evidence for the role of Black MSM in perpetuating the HIV health disparity among African Americans²⁸.

Mistrust/Conspiracy and Medication Adherence

Genocidal conspiracy beliefs appear to be the main barrier in HIV prevention campaigns and strategies, while treatment-related conspiracy theories appear to be at the forefront of issues with HIV medication adherence. Since the development of HIV medications, substantial research has been conducted to establish the impact and efficacy of these treatments on patients living with HIV. Medication adherence level has been directly connected with positive virologic and immunologic responses. Furthermore, patients who adhere to their medication regimes have lower risk for drug resistance and mortality²⁹. Thus, the importance of HIV medication adherence on survival rates cannot be overemphasized. Given that African American males continue to have the highest rate of HIV diagnoses³⁰, and that 1 in 6 African American males and 1 in 32 African American females will receive an HIV diagnosis in their lifetime⁷, it is surprising that African Americans are reported to have one of the lowest rates of antiretroviral treatment utilization and adherence³¹. Bogart et al (2011) has attributed these negative health care behaviors to medical mistrust, particularly, treatment-related conspiracy theories among the African American community²⁵. Medical mistrust regarding the intentions of physicians with respect to HIV treatment in addition to a more generalized skepticism about the efficacy of medications³² has led to this pattern of HIV treatment non-adherence. Unfortunately, these negative treatment-related behaviors have also resulted in poorer survival rates for African Americans as compared to their White and Hispanic counterparts^{7,33}.

Synthesis/Conclusions

Due to the ethical issues and concerns that surround conducting a randomized experiment on conspiracy theory and HIV-related behavior, research has only assessed correlations and not causation. Despite this, the research strongly suggests a relationship between medical mistrust, conspiracy beliefs and HIV-related behaviors among African Americans. A long history of medical experimentation and abuses of African Americans has led to feelings of vulnerability, suspicion and mistrust for institutions of medicine. This medical mistrust has persisted to the present day and has allowed health disparities to continue.

Research has illustrated that medical mistrust, particularly HIV-related conspiracy theories, have been associated with negative health-related attitudes and behaviors among African Americans. Beliefs that the government created HIV and is withholding the cure in order to systematically exterminate the African American race have led to maladaptive and self-destructive behaviors. African American males' rates of condom use and HIV testing are negatively affected by conspiracy beliefs. Also, due to these beliefs, an estimated 60% of African Americans living with HIV miss outpatient physician appointments and fail to follow physician treatment advice within the first year of diagnosis³³. Conspiracy theories and suspicions of medication and treatment efficacy underlie non-adherence to treatment. Ironically, African Americans' suspicions that medical institutions are trying to systematically eradicate their race have led to self-destructive behaviors, resulting in higher mortality rates for African American's with HIV²⁵.

Genocidal beliefs have been specifically identified as being most closely linked to barriers in HIV prevention efforts. Beliefs that HIV is a manmade virus have been associated with higher rates of unprotected sex and lower rates of condom use.

These negative health-related attitudes and behaviors have stifled HIV prevention efforts. Efforts to control HIV transmission may be more efficacious if physicians and health care personnel tackle genocidal conspiracy beliefs directly among African Americans. Prevention is key in controlling health care epidemics, and tackling the issue of genocidal conspiracy theories may be a crucial first step.

Addressing conspiracy theories among African Americans may significantly help to prevent the transmission and manage the treatment of HIV. Addressing medical mistrust among African Americans and reestablishing trust and credibility in medical institutions should be first and foremost. Government and public health agencies should have open conversations with African Americans and other minority groups to promote transparency within the topic of HIV. In addition, culturally relevant education campaigns should address historical causes of mistrust. Currently, much of the information circulating in Black communities regarding historical injustices against African Americans is inaccurate and often completely false¹⁰. Providing accurate details about past injustices will bring awareness to the issue of medical mistrust, and by acknowledging current cultural factors such as discrimination, racism and social stigma within health care settings, interventions to prevent and treat HIV may be significantly more successful.

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