



RESEARCH ARTICLE

# Medical Mistrust Among African American Living with HIV/AIDS in the Alabama Black Belt: The Impact of the U.S. Public Health Service Untreated Syphilis Study at Tuskegee

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OPEN ACCESS

## PUBLISHED

31 December 2024

## CITATION

Zekeri, AA., 2024. Medical Mistrust Among African American Living with HIV/AIDS in the Alabama Black Belt: The Impact of the U.S. Public Health Service Untreated Syphilis Study at Tuskegee. Medical Research Archives, [online] 12(12).

<https://doi.org/10.18103/mra.v12i12.6013>

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## DOI

<https://doi.org/10.18103/mra.v12i12.6013>

## ISSN

2375-1924

## ABSTRACT

**Background:** Despite prior studies showing that a significant proportion of the general African-American population held conspiracy beliefs about HIV/AIDS, limited research has investigated medical mistrust and conspiracy beliefs among African Americans that are HIV-positive and the subgroups most likely to endorse such beliefs. I examined the endorsement of HIV/AIDS conspiracy beliefs and medical mistrust among 356 African Americans living in the Alabama Black Belt region who are living with HIV infection.

**Methods:** Longitudinal quantitative and qualitative research (a mixed methods approach) were used in five rural counties of the Alabama Black Belt where two AIDS Outreach Organization clinics provide medical and social support services to HIV-positive persons. In a questionnaire, patients reported agreement with statements capturing beliefs in HIV/AIDS conspiracies and mistrust in American medical professionals and health institutions. Face to face focus group discussions and personal interviews were conducted with patients to determine reasons for medical mistrust. Focus groups and personal interviews were digitally recorded, transcribed, and analyzed.

**Results:** Results indicated that the majority of the patients (68.4%) somewhat or strongly agreed that “A lot of information about AIDS is being held back from the public.” More than one-half (65.6%) somewhat or strongly agreed that “people who take the new medicines for HIV are human guinea pigs for the government.” 61.2% strongly endorsed that “HIV is a manmade virus.” 62.2% strongly agreed that “AIDS was produced in the governments laboratories” while 59.7% strongly endorsed that “AIDS is a form of genocide against black.” Majority of the participants (91%) somewhat or strongly agreed that “they do not trust white medical practitioners and (70%) do not trust American Medical Institutions.” Participants of the focus groups raised the issue of the Tuskegee Syphilis experiment as a potential barrier, as well as the reason for the lack of trust.

**Conclusions:** The finding suggests that mistrust is a barrier to medication adherence among patients living with HIV/AIDS. The infamous Tuskegee Experiment was given as the main reason for the mistrust. In the years following the disclosure of the Tuskegee trials, the U.S. Public Health Service experiment is one reason African-Americans remain wary of mainstream medicine and health care providers. Negative past experiences contribute to medical mistrust among African Americans. Addressing medical mistrust and conspiracy beliefs should be the significant issues in HIV/AIDS treatment and prevention programs in the 21st Century.

**Keywords:** Medical mistrust, HIV/AIDS Conspiracy beliefs, African Americans, Alabama Black Belt.

## 1. Introduction

The human immunodeficiency virus (HIV) has become one of the major global health burdens in the 21<sup>st</sup> century. The human immunodeficiency virus (HIV), which causes acquired immunodeficiency syndrome (AIDS), is plaguing black communities across the United States. HIV/AIDS pandemic has created an unprecedented global health crisis. African Americans are infected at a disproportionately higher rate than other ethnic groups. Although they are about 13% of the population, African Americans make up 51% of HIV/AIDS cases reported in 2020 by the 33 states using confidential, name-based reporting.

The development of effective antiretroviral drugs is a crucial step in controlling the pandemic. Yet, the idea that AIDS was created as part of a government-led conspiracy to decimate the African American population remains influential to some black people<sup>1</sup>. Little is known about medical mistrust among HIV-positive patients in rural Alabama.

Treatment hesitancy differs across the United States. Understanding the reasons for hesitancy among African American populations will be crucial to inform scientific decisions on HIV/AIDS treatment in the 21<sup>st</sup> century. People living with HIV/AIDS worldwide form a vulnerable population that may be at risk of worse clinical outcomes from HIV infection and for whom antiretroviral medications may carry a particular benefit. However, medical mistrust related to the current or future HIV treatment to this population is not currently well understood.

Therefore, as an extension of my prior research<sup>1,2,3-7</sup> I want to determine if African Americans who are HIV-positive still hold some mistrust about American medical institutions and white professionals despite the factual medical information from different sources that are trustworthy. In my previous studies that examined the beliefs about the origin of HIV/AIDS as a genocidal conspiracy among African American and White patients living with HIV/AIDS<sup>3</sup>, I found that a significant proportion of African American patients living with HIV/AIDS endorsed HIV/AIDS medical mistrust. There is a research need to look into HIV/AIDS beliefs and medical mistrust because it may have implications for HIV/AIDS surveillance, public policy, and prevention programs.

In present research, I investigate the prevalence of medical mistrust and reasons for mistrust among African Americans living with HIV on antiretroviral therapy (ART). In previous research<sup>1,2,3,9-11</sup> I found out that African Americans that are distrustful of health care institutions are less likely to use healthcare. If efforts to prevent and also stop the spread of HIV/AIDS in black communities worldwide are to be beneficial, we should take into consideration the medical mistrust of African Americans with HIV. Patient factors such as beliefs in myths about HIV and distrust of the medical system may influence effective treatment of patients worldwide.

The manuscript is organized in four sections. The first is an introduction to the problem of the study. Section two

presents a detailed review of research methodology used in the study and describes the measurement and analytic procedures and the unit of analysis. The third section presents the findings of the analysis and discusses the results. The concluding section provides a discussion of the results, presents conclusions derived from the analysis and suggests implications of the findings for policy and further research.

## 2. Methodology

### 2.1 THE STUDY SITE

This is a longitudinal study conducted through personal interviews and field research between 25 August 2005 to 9 December 2023. The study area, Alabama's Black Belt, is part of the greater Black Belt region of the United States. The region is where most of the African Americans in Alabama live. While there is a distribution of African Americans across Alabama, many continue to be concentrated in the southern portion of the state (called the Black Belt and Mississippi Delta). Black Belt as used in this work designates the counties where African Americans outnumber the whites, that is the density of black people. The region is one of the poorest in America and the majority of the residents are welfare dependent. The Black Belt with its higher -than -average percentage of African Americans (about 90%) is home to persistent poverty, poor employment, unemployment, limited education, poor health, Temporary Assistance for Needy Families (TANF) recipients, single parenthood, and heavy dependence on public assistance programs<sup>9-11</sup>. The Black Belt is, indeed, a unique, disadvantaged region in the rural south. Other unique features of the area are rural decline, isolation, substandard housing, poor educational programs, high unemployment rates, poor economies, and limited access to quality health care.

### 2.2 STUDY POPULATION

The present study was part of a larger longitudinal project that examined HIV/AIDS and Food Insecurity in Alabama's Black Belt Counties (Bullock, Dallas, Lowndes, Macon and Wilcox). The parent study recruited 400 participants meeting eligibility criteria in five counties. At enrollment into the parent study, participants completed a baseline questionnaire assessing demographic characteristics, HIV care history, barriers to HIV care, competing needs, mental health, and social support, and agreed to be contacted later via telephone or in-person visit. For this current research, I contacted 356 participants enrolled in the parent study<sup>11</sup>.

The self-administered survey started at two AIDS Outreach Organization in Alabama that provides medical and social support services to HIV-positive persons in Southeast Alabama. For confidentiality purposes, only the staff of the AIDS Outreach informed the patients of the opportunity to participate in the study. The Adherence Nurse gave the questionnaire to patients and they completed the survey on a voluntary basis in a private room within the clinics. Participants provided verbal informed consent prior to filling out the structured questionnaire. The study protocol was approved by the human subjects review board of Tuskegee University.

2.3 FIELD RESEARCH

The objective of the focus group and personal interviews conducted in Bullock, Dallas, Lowndes, Macon and Wilcox Counties was to study the underlying beliefs and opinions on medical mistrust factors and their impact on HIV/AIDS and health disparities. African American participants that were HIV-positive were recruited from a HIV/AIDS clinic in Alabama. Others were recruited using a variety of methods, including community liaison recruitment and a snowball technique where African Americans from churches, barber shops, and beauty salons were encouraged to use their personal network and bring a friend to the focus groups. The community liaison was asked to recruit individuals to participate in the focus groups. This approach for recruitment was selected because individuals within the community have better access to residents and more credibility than a person outside the community. Potential participants were advised that: (1) focus groups would last one to two hours and be held at varied times during the day and evening and (2) they would be served a light meal during the meeting. They were advised that participation was optional and that they had the right to refuse to answer any questions and withdraw from the focus group anytime.

Written consent was obtained before starting the focus groups, and participants were provided light refreshments. The consent form and questionnaire were approved by Institutional Review Board at Tuskegee University. Before the focus group sessions began, participants were asked to complete a questionnaire. The questionnaire included questions on demographics and psychosocial variables. The demographic information allowed for a better snapshot of the focus group participants. The questionnaire also stated the purpose of the session. Ten focus group interviews were conducted over two years focusing on general perceptions of health and medical care general perceptions of health care providers and general perceptions of medical research. Each topic consisted of an open-ended question followed by a series of probes. I took notes during the sessions. This allowed information such as intensity of discussion, facial expressions, and other interpersonal communication clues to be recorded. These data are stored and locked in the author’s office.

2.4 HIV/AIDS RELATED MISTRUST

I adapted the conspiracy beliefs in Table 1 from my previous studies 1-3,9-11. Respondents were instructed to record their agreement with medical mistrust questions

and 10 statements capturing HIV/AIDS conspiracy theories (for example, “A lot of information about AIDS is being held back from the public,” “HIV is a manmade virus,” “AIDS is a real public health threat,” “There is a cure for AIDS, but it is being withheld from the poor,” “AIDS is a form of genocide against blacks,” “The government is not telling the truth about AIDS,” and “AIDS was created by the government to control the black population”). The scale was from 1 (disagree strongly) to 5 (agree strongly). The items were averaged and combined into one overall scale with higher scores indicating greater endorsement of HIV/AIDS conspiracies (Cronbach’s alpha = 0.93).

2.5. SOCIODEMOGRAPHIC VARIABLES.

Patients were asked questions to assess their gender, educational attainment, marital status, and age. Gender is sex of the respondent (1 = male and 2 = female). Educational attainment was measured by four categories: (1) did not graduate from high school; (2) completed high school; (3) some college or vocational school; (4) completed college. Education was dichotomized into “no high school” versus “high school and college graduates.” Age is age of the respondent in years. Age was dummy coded as young (18-34) and old (35-63) for the analysis.

2.6 STATISTICAL ANALYSES

Statistical analyses determine whether endorsement of conspiracy beliefs varied by socio-demographic variables were performed using the SPSS software version 14 (SPSS Inc, Chicago, Illinois) for Windows (Microsoft Corp, Redmond, Washington). Multiple linear regression analyses assessing the relationship between each of the sociodemographic variables to conspiracy beliefs scale were performed for the overall sample and by gender. The estimation of the probability that an association is not due to chance was based on chi-square statistics. A significance level of 0.05 was used for all analyses.

3. Results

SAMPLE CHARACTERISTICS

The sample is heterogeneous in terms of socio-demographic characteristics (Table 1). Of the 356 respondents, 50.6% were men. Over half were not married, and only 28.1% were married at the time of the study. A substantial proportion were 35 years or older. Almost a third had some college or vocational education, and 29.7% had a high school diploma.

Table 1. Participants demographic characteristics (n = 356)

Variables	n	%
<b>Gender</b>		
Male	180	50.6
Female	176	49.4
<b>Marital Status</b>		
Single	201	56.5
Married	100	28.1
Living with a partner	58	16.3
Separated	40	11.2
Divorced	30	8.4

<b>Educational Attainment</b>		
Did not graduate from High School	88	24.6
Completed High school	106	29.7
Some College or Vocational school	112	31.6
Completed a College Degree	49	13.7
<b>Age</b>		
0-21	71	19.9
22-34	126	35.5
35-63	158	44.5
<b>Health Insurance</b>		
Yes	173	48.6
No	133	37.4
<b>Employment Status</b>		
Working	228	64.0
Not Working	128	36.0

Results in Table 2 indicate that many patients endorsed conspiracy beliefs about HIV/AIDS. For example, more than half (68.4%) somewhat or strongly believed that, “A lot of information about AIDS is being held back from the public,” and 51.2% somewhat or strongly endorsed the statement that “HIV is a manmade virus,” while 55.1% agreed that “there is a cure for AIDS, but it being withheld from the poor.” About 66% believed that “AIDS was produced in a government laboratory.” More than half subscribed to the notion that “AIDS is a form of genocide against Blacks” and some 67.7% of the

respondents said that “AIDS was created by the government to control the black population.” Regarding treatment-related conspiracy beliefs, over one-third (65.6%) somewhat or strongly agreed that “people who take the new medicines for HIV/AIDS are human guinea pigs for the government,” while 56.9% somewhat or strongly endorsed the statement that “the medicine that doctors prescribe to treat HIV is poison.” In the bivariate analysis, gender was not significantly related to conspiracy beliefs about HIV/AIDS.

Table 2. Percentage of Participants who agreed with HIV/AIDS Conspiracy Beliefs and Medical Mistrust (n= 356)

	Overall (n=356)
<b>HIV/AIDS Conspiracy Beliefs</b>	
A lot of information about AIDS is being held back from the public	68.4
HIV is a manmade virus.	61.2
AIDS is a form of genocide against blacks.	59.7
The government is not telling the truth about AIDS	57.3
AIDS was created by the government to control the black population.	67.7
There is a cure for AIDS, but it is being withheld from the poor	55.1
The medicine that doctors prescribe to treat HIV is poison	56.9
People who take the new medicine for HIV are human guinea pigs for the government	65.6
AIDS was produced in a government laboratory	66.2
<b>Medical Mistrust</b>	
I do not trust white medical professionals	91.0
I do not trust the American medical Instructions	70.0

Significant values are based on X<sup>2</sup> tests between women’s and men’s frequency distributions of the 5 category responses to each item (disagree strongly, disagree somewhat, no opinion, agree somewhat, agree strongly), df = 4.

## Medical Mistrust in White Professional and Medical Institutions

More than half subscribed to the notion that “I do not trust white medical professionals (91.0%) and 70% of respondents said that they “do not trust the American medical institutions.”

### Who is More Likely to Express HIV/AIDS Mistrust?

Results of the regression analysis predicting beliefs in conspiracy beliefs not reported here indicate that expression of such beliefs was more among young African Americans and the less educated.

### Why HIV-Related Mistrust and Medical Mistrust?

When asked why they did not trust the white medical professionals, one respondent said:

*“White people are not good. Don’t you read or hear about what they did in Macon County, Alabama to black people? We don’t trust them. Researchers disclosure of the infamous Tuskegee syphilis study in 1972 has led us not to trust white medical doctors. It has increased in medical mistrust and mortality among us African-American people. They can kill you”*

One woman said:

*“We African-Americans are wary of medicine and health care providers. It’s been more than 40 years since the revelation of the Tuskegee syphilis study sent shockwaves across the country. The current mistrust of the medical community among African-American people appears to have spread far beyond the Deep South, where the infamous public health project took place.”*

Another man who is 60 years old said that:

*“The legacy mistrust is stemming from Tuskegee Syphilis study experiment that began in 1932 and ended in 1972.”*

Another 30-year-old male agreed with the above statement and said:

*“We are motivated by historical research on the role of Tuskegee shaping our health behaviors. Remembering this medical horror story growing up in neighboring county, I vowed to become a doctor and help revive the lost trust in public health in the Deep South.”*

A college-educated woman said that:

*“The Tuskegee study has become synonymous with exploitation and mistreatment by the medical community.”*

As one Registered Nurse put it:

*“I believe that even if you remove all the obstacles – transportation, access to health care and insurance these Black Belt Counties – if you don’t trust the provider, you won’t follow their advice. But if you can push through this issue of mistrust, then you really begin to reap the benefits of the wealth of our health care system. Medical mistrust does not have to dissuade black men from seeking health care in contemporary America – but it does.”*

Another person said that

*“Tuskegee experiment is shaping health care behaviors among African American.”*

### Lack of Trust in White Health Professionals

The main issue that came out of the interviews and discussions is distrust in white health professionals. African Americans are more reluctant than whites to seek treatment for HIV and AIDS because they distrust the government<sup>6-8,10-11</sup>. This is because of the infamous Tuskegee Experiments conducted by the U.S. government for 40 years (from 1932 to 1972). For the experiments, 399 poor black men were recruited and led to believe that they would receive free medical treatment for what they called “bad blood,” while, in fact, they were left untreated for syphilis so that the government health researchers could study the impact of the disease on them.

**Adherence to treatment:** During the interviews, I found that the consequences of conspiracy beliefs can affect adherence to treatment. Some patients indicated that disbelief in medical white people was an overarching barrier to adherence to treatment. Some said that because some of their HIV medicines require taking them with food, they skip taking them when they don’t have food.

Susan, a 40 year-old woman frankly told of various time she skipped her medication because she has no belief in them: *“I usually don’t take my many medicines because I do not trust them. The medicines will make you sick in the stomach and they can kill you. Therefore, I do not take my medicines regularly as prescribed.”*

## Discussion:

My study is the first of which I am aware to explore how medical mistrust among HIV positive African Americans in the rural south is related to the Tuskegee Syphilis study. Prior research has similarly found that HIV-related mistrust in the form of conspiracy beliefs is endorsed by a substantial proportion of African Americans that are HIV positive<sup>11</sup>. The present work takes my previous work a step further, by examining why mistrust of the medical practitioners. The results suggest that the Tuskegee Study may have impact on people living with HIV having mistrust about the white medical practitioners and the American medical intuitions.

This is crucial because mistrust of healthcare professionals and organizations has been associated with less treatment adherence, less utilization of healthcare services and less care satisfaction<sup>1,2,3</sup>. This may be also contributing factors to the disparity in health care in the rural south.

Not surprisingly, age and education were identified as significant variables influencing beliefs in HIV conspiracy. Notably, increased educational attainment exerted a more substantial impact on belief behavior compared to other socioeconomic variables. This finding is consistent with existing literature, which indicates that individuals with higher education tend to avail themselves to belief in HIV conspiracies,

Findings have implications for future HIV related research. My study shows that mistrust persists at a higher rate

among African Americans, suggesting that structural interventions are critical to address the roots of medical mistrust as well as discrimination, including the wider historical and present context of structural discriminations in health care. Health care providers should be made aware of the historical context of discrimination that may be influencing African Americans to behave the way they do as well as the prevalence mistrust among patients.

As the last of the Tuskegee Study survivors, Ernest Hendon, who died in 2004 at the age of 96, put it:

“The wounds that were inflicted upon us cannot be undone,” He said at the White House ceremony, after being helped to the podium by Clinton. “I’m saddened today to think of those who did not survive and whose families will forever live with the knowledge that their death and suffering was preventable.” Two years earlier, at the White House ceremony, he still found it in his heart to say it was never too late to “restore faith and trust.” “In order for America to reach its full potential,” he said, “we must truly be one America – black, red, white together – trusting each other, caring for each other and never allowing the kind of tragedy which has happened to us in the Tuskegee study to ever happen again.”

My qualitative findings were consistent with the notion above, as men expressed the challenge of setting aside their usual reluctance to engage with the healthcare system when confronting HIV/AIDS. They discussed feeling compelled to take control of their lives, driven in part by their mistrust of the system and the need to monitor their health closely. While majority exhibited high levels of distrust, the underlying reasons was predominantly attributed to historical precedents. Tuskegee Syphilis study increased the highest levels of medical mistrust

## Conclusion

My study indicates that mistrust, in the form of HIV/AIDS Conspiracy beliefs and white medical professionals is actively present among African Americans living with HIV/AIDS, and that these mistrusts are influenced by the Tuskegee syphilis study. Mistrust was motivated by historical research on the role of Tuskegee study shaping health behaviors. Future research is needed to determine on how to mitigate the root of mistrust, as well as how to stem the spread of medical mistrust, which may be contributing to HIV related disparities in treatment adherence.

Focus group discussions suggested that conspiracy beliefs can be important barriers to quality of life and infection control among HIV-positive individuals. Conspiracy

beliefs can reduce medication adherence. Some patients indicated missing their medications. This can affect the viral suppression that underpins optimal health for HIV-positive individuals. Therefore, conspiracy beliefs as a correlate of antiretroviral success must be addressed by HIV clinicians.

Overall, these findings suggest that HIV/AIDS conspiracy beliefs and medical mistrust among African Americans must be acknowledged and addressed in culturally-tailored HIV/AIDS prevention and education programs. This is because these conspiracy beliefs may be a barrier to HIV prevention and treatment efforts to halt the epidemic in African American communities where it is taking a terrible toll.

## Limitations of the study

The study does have some limitations. The sample size is small. Additional research on these issues with a larger sample is needed to understand the breadth and complexity of beliefs in conspiracies about HIV/AIDS and relationships to sociodemographic variables. Place of residence

was not considered in this study. Future research is needed to examine the contribution of this important variable to conspiracy beliefs. We want to know if there are differences among African American in rural and urban areas with regard to HIV/AIDS conspiracy beliefs and medical mistrust. Additionally, I relied on self-reported data, raising the possibility that respondents may have responded in a socially desirable manner. My success in recruiting large numbers of African Americans through diverse recruitment sites such as local barber shops, local churches, community centers, hair salons, and organizational groups, underscores the strength of my research method.

In sum, it is recommended that all those involved in the battle against HIV/AIDS in African American communities (health workers, social workers, individuals, community organizations, and government agencies) must give special consideration to prevention and treatment efforts that will significantly reduce the incidence and prevalence of HIV/AIDS among African Americans in the Deep South.

**Acknowledgements:** I would like to acknowledge the participants for being a part of the research,

**Disclosure:** The author reports no conflict of interest in this work.

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