

African-Americans Trust and Mistrust in Healthcare System

An Honors Thesis (HONR 499)

by

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Abstract

There is no doubt that medical trust and mistrust exists within the African American community. Mistrust could have stemmed from past experiences including the Tuskegee Syphilis Experiment, the use of HeLa cells, named after Henrietta Lacks, without her family knowing, and using enslaved African American women to test out gynecology procedures in the early 1800s. The purpose of this thesis is to measure the trust and mistrust African American's may have with the current healthcare systems and staff. With my personal experiences and opinions of the healthcare systems, I also know a wide range of other individuals whose trust in the healthcare system no longer exists due to mistreatment and false diagnosis. I would like to shed light on a topic that has gone unnoticed, but is recognized in our communities, but no one is raising awareness on the topic and there has not been a study done in 10 years. To help shed light on the topic, I also performed a study where data was collected and analyzed on medical mistrust in a community-based population of African American men and women and test the relationship between medical mistrust, health outcomes, and healthcare utilization. Data was collected from local churches in the East Chicago and Gary communities and community members were recruited to take a brief online survey. Results indicate an association between medical mistrust and healthcare utilization.

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Process Analysis

Exploring African American's medical trust and mistrust was not a topic I came across easily. I came to the conclusion that I wanted to explore medical mistrust and trust amongst other African American men and women after having some bad experiences with the healthcare system myself. My bad experiences occurred in the spring of 2018 and the fall of 2019 at the local hospital near campus. I had to go to Chicago to receive proper medical treatment which resulted in two emergency procedures. If I needed to seek medical treatment, I would wait until I was able to go home. If I could not go home, I would travel to Indianapolis for treatment. During my short time volunteering at a few hospitals, I was able to see how the staff interacted with patients and whether the patients were being tended to. For the most part, all patients were being tended to, but for African American patients, they were often forgotten. They would call out for the nurse or doctor, but the nurses would send volunteers into their rooms to see what they wanted. After having a few conversations with my grandparents, my peers, and a few physicians, that I realized that medical mistrust still exists among the African American culture and needs to be discussed in our communities.

Through this process of intense research, I started to compare the treatment I received at my home, Northwest Indiana and Chicagoland area, healthcare organizations and doctors versus the treatment I received near campus. Near campus, my symptoms were not taken seriously, I would always wait several hours before they came in with any results, and in the end, they would glance over my medical records and send me home. Pregnancy tests are their solution to everything. I would have to beg the nurses and doctors to look further and this request resulted in very rude and disrespectful behavior on the nurse's behalf. Near campus, I felt as though my health was not a priority. I also noticed that my diagnosis, test results, and doctor's notes were

never uploaded to MyChart account, after any of my visits. At home, they make my health a priority. They run the necessary exams and blood work, they are through with everything, and they frequently update my MyChart account. There is a distinct difference in the way I am treated in both locations, so I go home for medical care.

Through the process of research, I discovered that medical trust and mistrust could have started during the nineteenth century, when James Marion Sims, the Father of Gynecology conducted research on women in slavery without medical ethicists and no anesthesia. Trust and mistrust could have also stemmed from the Tuskegee Syphilis Study in 1932-1972, where African American men were infected with the disease without their knowing. The common topics in past research studies, measured the trust and satisfaction in healthcare systems between white and African Americans. With these past research studies, they were able to help me come up with questions and statements to ask in my personal research study. These studies also helped me to understand that mistrust could stem from a variety of factors such as personal experiences, hearing about other experiences, the treatment received while at a healthcare facility, lack of healthcare and transportation, and the biggest factor, believing that the doctors are infecting them with an illness, instead of helping them out. Very few articles discuss the mistrust in healthcare systems. I struggled to find recent and past studies solely devoted to measuring the trust and mistrust African Americans may have with the current healthcare system, in predominantly black communities and college students. Because of the lack of studies and research done to measure the trust and mistrust in African American men and women in predominantly black communities and college students, I conducted my own research on this specific topic.

While I was unable to conduct interviews for my research based on timing and COVID-19, I was still able to gather data via online survey and comparing my data to previous studies

completed. I was also able to go into African American communities within Northwest Indiana and reached out to African American college studies at Ball State University. Although I had to adjust my process and analysis of my research, I was still able to measure the trust and mistrust in the current healthcare system. The culmination of my thesis has pushed me out of my comfort zone and allowed me to conduct my first study and helped me realize that I have the potential to do research, when I stop doubting myself.

If I were to do research again, I would like to conduct interviews and reach out to more African American communities in Indiana. While mistrust may be ongoing, further studies can be done to try and combat the areas of mistrust in the healthcare system. With more studies, a more in-depth analysis of mistrust and trust can be measured to show the areas of concern. And possibly compared to other minorities trust and mistrust in the healthcare systems.

Introduction

“There is strong empirical evidence of health care disparities between black and white Americans. Blacks are less likely than are whites to receive many needed services, including routine preventative care”, stated Musa and colleagues (2009). Structural and socioeconomic differences and characteristics are sources of care disparities and that racial bias in the healthcare system is also a major factor in disparities in care between whites and blacks (Musa et. al. 2009). Mistrust in the healthcare system amongst African Americans is well recognized in society, however, it is not widely discussed on major media platforms. According to Benkert (2006), discriminatory treatment of African Americans in healthcare is well recognized, yet literature is unclear on the specific role perceived racism and mistrust play in the patient-provider relationships (Benkert, 2006). The explicit and implicit racism that is displayed during healthcare visits occurs when the physician overlooks important health issues of blacks based on lack of knowledge and race (Benkert, 2006). In medical research and clinical settings, America has a well-documented racial discrimination concerning African Americans (Mays et. al., 2007). For example, the United States Public Health Service Tuskegee Syphilis Study on Untreated Syphilis in the Negro men, where health officials withheld treatment for these men (CDC, 2020). In the 1800s, James Marion Sims conducted harsh gynecology procedures on enslaved women to help improve surgical procedures in the future (Wall, 2006), and HeLa cells from Henrietta Lacks. In the biography, *The Immortal Life of Henrietta Lacks*, a biography by Rebecca Skloot that discusses Lacks’ history through her families point of view. Lacks was dehumanized after biologist George Otto Gey discovered that her cells proliferate abnormally and began using and selling her cells without her family knowing anything (Khan, 2011). As a result, her family was unable to benefit financially off of their loved one’s cells (Skloot, 2010). Along with well-

documented behaviors of healthcare providers, personal experiences with healthcare organizations and physicians also help shape the mistrust and trust that African-Americans may have in the current healthcare systems.

The purpose of this study was to measure the trust and mistrust African-Americans may have in the healthcare system. This study used past studies to help develop a questionnaire based on measuring both trust and mistrust in African-American adults, whereas past studies only focused on the mistrust between blacks' versus whites. The main goal was to explore where African-Americans stand on trusting their healthcare providers.

Trust and mistrust in the healthcare system has become an issue in the United States. According to Dr. Corey J. Williams, many black Americans do not trust their healthcare providers to act in their best interests (Williams, 2017). Research has shown that blacks are much less likely to report trust in their physicians and hospitals; thus, they are less likely to seek treatment or be compliant with recommended treatment plans (Williams, 2017). Compared to white Americans, African-Americans are much more likely to die from asthma and cancer (Williams, 2017). Because of the lack of recent studies done in the United States, more evaluations need to be conducted to come up with ways to combat mistrust in the healthcare system (Armstrong et. al., 2006). More importantly, this topic needs to be addressed on major media platforms to further raise awareness and help fellow African Americans get the fair treatment they deserve with healthcare organizations and their staff (Taylor, 2020).

Methods

The study relied on a systematic literature review of articles about trust and mistrust that African-Americans may have with their health care providers, centers, and staff. The study also relied on past questionnaires from the literature review articles. The two databases used to find

seven articles were PubMed and Google Scholar. To locate programs in these databases, the following keywords were used: “distrust”, “mistrust”, “African American”, “health”, and “disparities”. Of the articles chosen, the references were used to search for relevant and additional studies in the United States. An original investigation was also used where an online questionnaire was given to African American men and women ages 18 and up, in predominantly black communities in Northwest Indiana.

Analysis

Once the studies were found, they were then assessed for methods used, their definition of trust and mistrust, and the overall results of the study. Most of the articles used the term “distrust” than the term “mistrust”. Between all of the studies, the common ground each discussed was the mistrust African-Americans may have in their healthcare providers, while being compared to white Americans. The studies lacked the discussion about trust in healthcare providers. The studies were completed in various places, with none being completed in predominantly black communities. There were very few studies that only discussed African-Americans. None of the articles had a personal view or outlook into why African Americans have trust or mistrust in their healthcare providers. The definitions of trust, mistrust, and distrust were then analyzed for consistencies within each article. The results or the main findings in each article were assessed to determine whether their findings were similar. After these themes were assessed, a questionnaire was developed to be deployed in predominantly black communities to address both the trust and the mistrust of African-Americans in healthcare systems.

Results

The analyses revealed that 80% of participants were female, while 20% percent of the participants were male. The online survey had 227 participants. Analyses also revealed that

19.91% of participants are not employed, 40.27% work less than 40 hours a week, and 39.82% work more than 40 hours a week. The education levels also varied with 8.28% having a high school diploma, 43.75% with some college, 30.36% graduated college with a 4-year degree, and 17.41% have a master's or doctorate degree. Approximately 95% of participants are insured, whether its Medicare, Medicaid, through their employer, personal savings, or their spouse's employer. The majority of the participants stated that their health is good. Common chronic diseases are asthma, high blood pressure, breast cancer, endometriosis, lupus, various types of arthritis and autoimmune disorders, obesity, high cholesterol, and chronic migraines. In Table 1, you will find summarized results of some questions from the online questionnaire.

Table 1. Summarized data based on major points.	Strongly Agree	Agree	Disagree	Strongly Disagree
If my doctor tells me something, then it must be true.	6.67%	46.22%	41.78%	5.33%
Certain types of patients get better care from healthcare organizations than most other patients.	38.50%	49.56%	11.06%	0.88%
We have to be cautious when dealing with healthcare organizations.	27.68%	62.09%	9.38%	0.89%
I doubt my doctors care about me as a person.	4.46%	13.84%	63.39%	18.30%
I sometimes distrust my doctor's opinions and would like a second one.	11.56%	32.89%	50.22%	5.33%
I trust my doctor's judgements about my medical care.	14.22%	74.67%	10.67%	0.44%
Patients get lost in the healthcare system because of all the paperwork.	16%	47.56%	34.22%	2.22%
I trust healthcare organizations to only recommend care that I really need.	6.64%	51.33%	35.84%	6.19%
When healthcare organizations make mistakes, they. Usually cover it up.	18.58%	53.98%	26.11%	1.33%
Healthcare organizations do not always keep our information totally private.	12.44%	44.44%	36.44%	6.67%
Sometimes I wonder if healthcare organizations know what they are doing.	16.89%	49.78%	30.67%	2.67%
Mistakes are common in healthcare organizations.	20%	59.56%	19.56%	0.89%
Patients are sometimes not told the truth or mislead by healthcare organizations.	20.44%	50.67%	27.56%	1.33%

Some people feel that the way they are treated depends on factors such as what type of medical insurance they have, their gender, and their race as an African-American male or female, determines what kind of treatment they will receive at any healthcare organization. Some people expressed that they changed doctors and currently have a good team of physicians they trust and have their interest at heart. Pregnant women seem to be the ones with the worst experiences with the healthcare system during their pregnancy. In Figure 1, participants were asked to choose all options that apply to them within the last two years. Within the last two years, 14.23% did not do what the doctor said, 21.17% did not seek medical care when they thought they needed it, 13.50% did not fill a prescription that was needed, 26.64% refused to seek medical attention, and 24.45% failed to follow-up with their doctors.

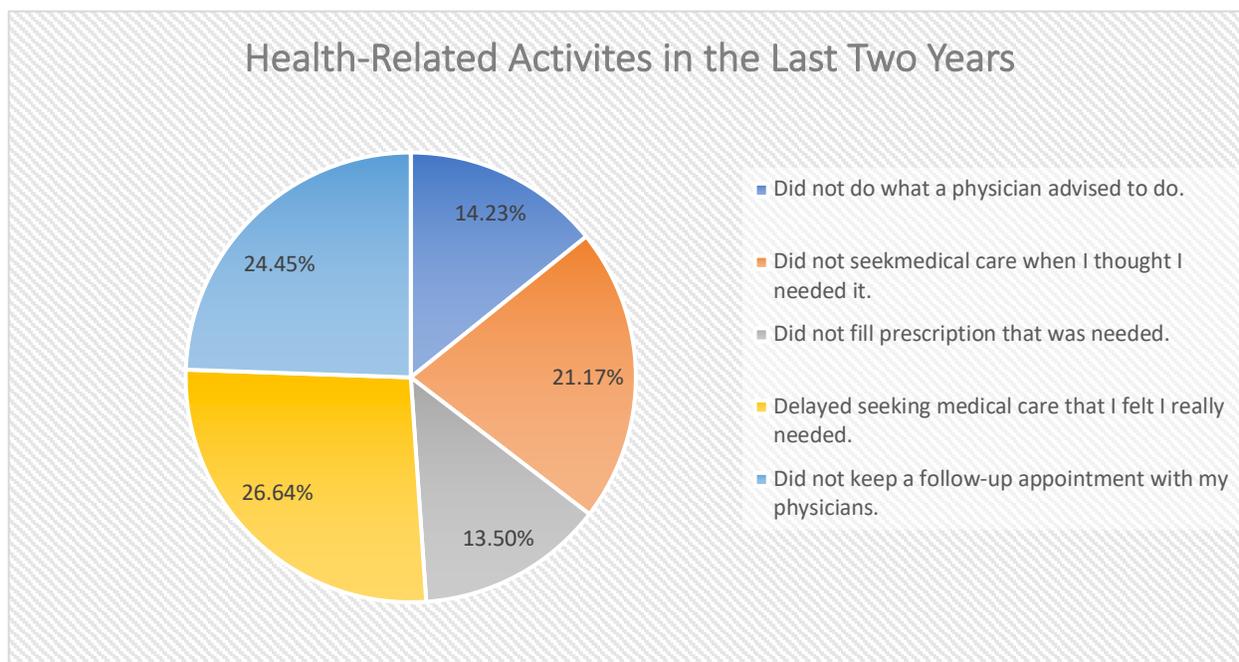


Figure 1. Participants were asked to check all that apply within the last two years.

Discussion

The purpose of this study was to measure the trust and the mistrust African Americans may have in today's healthcare system. Terms trust, mistrust, and distrust did not have a

consistent definition among the studies. The lack of consistent definitions raised questions as to what factors helped define what trust, distrust, and mistrust meant in each study. I identified both trust and mistrust amongst the participants. Common age range of participants was between the ages of 20 and 42.

Compared to other studies, they have found interpersonal among their research participants. “Interpersonal trust can be defined as having the perception that someone will do anything to harm your interest”, (Williams pg.3). These studies included perceptions of both blacks and whites. Few studies focused on African-Americans alone. The data received in the independent study had very few similarities with other study data. The types of questions and platforms used to engage participants varied across the board and included a wide range of participants. Most studied focused on accessing preventative care, how often African-American women received mammograms and cancer screenings, and the overall trust or distrust that could be in black and white communities. Black and white communities were often used in comparison where the white communities always a high percentage rate of trust had while seeking medical care. For black communities, the opposite occurred where the percentage of distrust or mistrust was high, but their trust low.

Major findings include:

- That both trust and mistrust exist among the participants
- Those with a master’s or doctorate degree, have better experiences with healthcare organizations.
- Women and men age 20 to 35 have the worst experiences with the healthcare system.
- Many believe that people of certain race, tend to have better experiences with the healthcare system.

- Many trusts their doctor will give correct diagnosis and treatment options.
- Mistakes are common in the healthcare system.
- Pregnant women have a hard time seeking medical attention when they feel discomfort during their pregnancy.
- Many trusts that their doctor cares about their well-being.
- If participants never had a bad experience with the healthcare system, they know other people who have had bad experiences
- Majority of the mistrust comes from personal experiences and stories shared by peers.
- Medical insurance determines what type care you will receive when seeking medical attention.
- Many have underlying health condition due to having a lower access to care.

What do major findings mean:

- Women have the worst experiences with the healthcare system and often do not get taken seriously when they do seek medical attention.
- Men only seek medical care when the illness or pain gets worse.
- When comparing trust and mistrust among participants, trust and mistrust is almost 50/50.
- If you have a high education level and great medical insurance, you often receive better care than someone who had no education.
- Most people have insurance through their employer, or they have Medicare and Medicaid.
- Mistrust can be associated with bad medical outcomes.

How can the major problems be fixed:

- Fostering trust between patients and physicians is an important way to increase preventative service use (Musa et al 2009).
- Patients can become educated on their symptoms and diseases
- Healthcare organizations and its staff should take full responsibility for their injustices.
- Healthcare workers should work together to combat medical injustices.
- Healthcare system should engage minority races in candid conversations about why they have mistrust in the healthcare system, so that they can learn improve,

What are the future research studies that need to happen-

- Assessing the needs of pregnant women in the healthcare system
- Comparing how the elderly and younger generations trust and mistrust the healthcare system
- Why the older population may not trust their doctors?
- Comparing African-American trust and mistrust with other minority groups.
- Assessing the trust and mistrust between people with chronic diseases or illnesses such as cancer, heart disease, and type 2 diabetes.
- How frequently women go get mammograms and yearly check-ups with their OB/GYN?

What are the tips and guidance for healthcare practitioners:

- More training can be given to address treating illnesses and diseases from culture to culture.
- Keep in mind that the patient may already have doubts about a doctor's ability to resolve the medical issue.
- Everyone does not have great experiences with doctors/nurses
- They should be fair to all patients when they seek medical attention.

There will always be some kind of mistrust in the healthcare system. The only thing we can do to prevent mistrust from reoccurring, is to bring awareness to the situation. Patients should engage in conversations with their doctors so that a common ground could be found to help improve the treatment of other people. This allowed me to see this topic from a very different perspective. I was able to engage other people about a topic they also felt should be discussed more in our world today. I learned that I am not the only person who has had bad experiences with the healthcare system. The study helped me to see that the better education and medical insurance you have, you may have a greater trust with their healthcare organization and doctors. Everyone is not educated on what causes their symptoms, they do not fully understand their disease(s) or illnesses, and they lack the common knowledge needed when seeking medical care such as their rights and protocol. Mistrust varies between people because their mistrust could stem from personal experiences and perceptions or from famous studies such as the Tuskegee Syphilis study and the use of HeLa cells. Future studies should be done to dig deeper into this topic and to help find ways to combat mistrust in the healthcare system with everyone.

In March of 2020, the United States declared coronavirus as a pandemic. On March 31st, 2020, the CDC released a report stating that people with diabetes, chronic lung disease, and those that smoke, have a higher risk of developing severe complications if they get infected with coronavirus (Lovelace Jr., 2020). African-Americans suffer from diabetes and a wide range of chronic lung and heart illnesses due to the fatty foods they consume. With a lack of trust in healthcare systems, African Americans may have a higher risk of contracting the virus. We have to also keep in mind that not all African Americans have access to affordable healthcare, hospitals and clinics, and many other inequalities that they face in the United States.

My findings may be relevant in the COVID-19 pandemic because African-Americans have a higher infection and mortality rate, than any other race. Along with having a higher infection rate and mortality rate, African Americans have longstanding inequalities such as seeking appropriate medical attention and fresh food and produce (Lovelace Jr., 2020). African Americans also disproportionately represent workers who are not able to work from home, as they are deemed essential, putting them at more risk for contracting the disease. According to the CDC MMWR report, out of 580 patients 59% of the individuals tested positive for COVID-19, while 33% of hospitalized patients were black, compared to 18% in the community, and 8 % were Hispanic, compared to 14% in the community (CDC, 2020). “Black Americans continue to make up a disproportionate share of COVID-19 fatalities as the number of deaths from the Coronavirus pandemic exceeds 100,000 in the United States”, according to an analysis of data from the Centers of Disease Control and Prevention (CDC), (Lovelace Jr., 2020). New York City has identified death rates among African American people (92.3 deaths per 100,000 population), while Hispanic/Latino individuals (74.3), with of which are higher than that of white (45.2) or Asian (34.5) individuals (CDC, 2020). Although African-American individuals make up roughly 13% of the United States population, they make up 23% of the reported COVID-19 deaths, as of May 20, 2020 (Lovelace Jr., 2020). COVID-19 deaths by state surpass the population of African Americans residing in that state. In Georgia, African Americans represent 32% of the state's population, but account for approximately 47% of COVID-19 deaths, according to the CDC (Lovelace Jr., 2020). In Michigan, African American make up 14% of the population and account for 39% of deaths, while, African Americans make up 33% of Louisiana’s population, but account for 54% of COVID-19 deaths, according to the CDC (Lovelace Jr., 2020). New York City is the epicenter of the coronavirus outbreak. African-Americans and people living in

lower-income communities have been greatly affected by the coronavirus, compared to other states, expresses Mayor Bill de Blasio (Lovelace Jr., 2020). In Georgia, Louisiana, Michigan, and New York City, low income neighborhoods have been greatly affected by the virus. These low-income communities may lack appropriate healthcare clinics and hospitals', transportation may be limited, and these communities may not have access to healthy and organic produce and foods. Along with these four states, the rest of the states show similar results, with African-Americans being greatly affected by coronavirus.

From the various news stories to the private testimonies of some African-American coronavirus survivors, the treatment they received in the hospitals were not great and they witnessed white Americans receiving better care than that of Hispanic and African American patients. My aunt and uncle are survivors of coronavirus and they were in disbelief at the lack of treatment and care they received while at the hospital. My aunt vividly remembers a nurse coming in the room to check her breathing and temperature, but the nurse refused to check her vitals and change the pressure of her oxygen tank. Her neighbor was a middle-aged white woman and my aunt says she got treatment and was well looked after the entire time she was here. As a result, she went home three weeks before my aunt and uncle recovered. Compared to white Americans, my aunt stated that African Americans took longer to recover because of the lack of care and treatment they are receiving at the hospital. "What makes this whole experience worse is that you cannot have loved ones in the room to protect you and look after you to make sure the doctor and nurses are doing their jobs. It scares me that they may be intentionally killing African-Americans and they have to suffer alone", states my aunt. My aunt's experiences compared to my personal experiences are similar in the lack of treatment and care received when seeking medical attention and witnessing other patients receive the best care.

A vaccine has yet to be found and tested, but there have been talks to test the vaccine on African-Americans, being that African-Americans have been disproportionately devastated by coronavirus. “The head of the World Health Organization (WHO) has condemned as “racist” the comments by two French doctors who suggested a vaccine for the coronavirus be tested in Africa”, (BBC News, 2020). During a debate about the coronavirus, Dr. Jean-Paul Mira states, “If I can be proactive, shouldn’t we be doing this study in Africa, where there are no masks, no treatments, no resuscitation?” The comments stated by the doctors had fueled worry and speculation in Africa, that they will be used as guinea pigs for a new coronavirus vaccine (BBC News, 2020). The WHO goes on to state that Africa will not be a testing ground for a vaccine (BBC News, 2020). In an article by Curtis Bunn (2020), experts state that a COVID-19 vaccine will only work if trials include black people. Caletia Hodges is a clinician at Infinite Clinical Trials in Atlanta and her task is to persuade black people who have a deep mistrust of experimental drugs and medical institutions to participate in clinical trials to help find a vaccine for coronavirus (Bunn, 2020). The experts go on to state that a vaccine might not work in African-Americans if they do not participate in the trials to create a drug. Participation in this trial is critical because different genetic factors affect reactions to drugs, which medicine could produce different results based on race and genetic, socioeconomic and environmental dynamics (Bunn, 2020). “The reason I hear African Americans will not participate are heartbreaking. And disappointing,” Hodges said “I have heard about the Tuskegee experiment a lot. And I have heard “They [doctors] will give me the virus.’ And “They will put a chip inside of me.’ Many say their parents raised them ‘to never participate in medical research.’ It is tough to overcome.” (Bunn, 2020). According to Dr. Larry Graham (Bunn, 2020), he understands the lack of trust but insists that African-Americans have to get over it.

All in all, if African Americans do not participate in coronavirus vaccine trials, then there will be no new vaccine to help cure the virus. It is upsetting to hear that scientists are suggesting that vaccine testing should be done in Africa or that a new vaccine will only work if African-Americans are used in the study. Past medical experiments such as the Tuskegee Syphilis Study, are events that one cannot forget nor get over it. The mistrust displayed by African-Americans comes from a wide variety of reasons, from bad experiences in the healthcare system to unfair treatment by medical professionals. In my findings, I found that low-income neighborhoods have a higher mistrust when seeking healthcare because of no health insurance, lack of transportation to seek attention, and these neighborhoods do not have access to good, healthy organic produce or food. I also found that African-American women do not get fair treatment at healthcare organizations, and with the coronavirus, African-American women compared to men have been disproportionately affected by the virus. The following findings of my research apply to the coronavirus as well:

- Women and men age 20 to 35 have the worst experiences with the healthcare system.
- Many believe that people of certain race, tend to have better experiences with the healthcare system.
- Mistakes are common in the healthcare system.
- Majority of the mistrust comes from personal experiences and stories shared by peers.
- Medical insurance determines what type care you will receive when seeking medical attention.
- Many have underlying health condition due to having a lower access to care.
- Women have the worst experiences with the healthcare system and often do not get taken seriously when they do seek medical attention.

- Mistrust can be associated with bad medical outcomes.

The more articles I read and the more news I watch, I grow worry with fear that the inevitable will happen to my race, causing their mistrust in healthcare system to deepen. It is upsetting that African-Americans are disproportionately devastated by the coronavirus due to a vast majority of inequalities that we continue to face each day while in the United States. I was asked “does mistrust contribute to African Americans suffering much higher infection and mortality rate?”, and I do believe mistrust is a big contribution to high infection and mortality rates. I state this because many people are scared to get tested, in fear that they may be implanting microchip or that they will test positive and have to go to the hospital. Although the virus is very serious, I found that some African-Americans are not willing to get tested because they do not want to be in the hospital suffering alone, they do not have anyone there to make sure they are getting the proper care, and if they do not have access to good health insurance, paying out of pocket may hurt them financially. Also, during this time, past experiments such as the Tuskegee Syphilis Study and the father of modern gynecology (J. Marion Sims) experimenting on enslaved African American women, have resurfaced to educate everyone about the horrific medical experiments done on African-Americans without their knowledge and without consent. Because of these past experiments, many believe that they may try to use African-Americans to test out a vaccine for coronavirus, only causing more mistrust in the healthcare system and its team of professionals and scientists. Mistrust will always exist as long as healthcare organizations resist to change and stop unfair treatment of African-Americans. Although mistrust will never go away, I would like to thank medical researchers and coronavirus patients and survivors for speaking out about the medical mistrust African-Americans endured when trying to seek medical care or while they were battling coronavirus. I will continue to expand my research

in years to come. I will not give up until all African-Americans get fair and equal treatment in the healthcare system.

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Office of Research Integrity
 Institutional Review Board (IRB)
 2000 University Avenue
 Muncie, IN 47306-0155
 Phone: 765-285-5052
 Email: orihelp@bsu.edu

DATE: March 18, 2020

TO: E'Staria McFerrin

FROM: Ball State University IRB

RE: IRB protocol # 1548272-1

TITLE: African American's Trust and Mistrust in Healthcare Systems

SUBMISSION TYPE: New Project

DECISION: APPROVED

PROJECT STATUS: EXEMPT

DECISION DATE: March 18, 2020

REVIEW TYPE: Exempt Review

The designated reviewer for the Institutional Review Board (IRB) reviewed your protocol and determined the procedures you have proposed are appropriate for exemption under the federal regulations. As such, there will be no further review of your protocol, and you are cleared to proceed with the procedures outlined in your protocol. As an exempt study, there is no requirement for continuing review. Your protocol will remain on file with the IRB as a matter of record. All research under this protocol must be conducted in accordance with the approved submission and in accordance with the principles of the Belmont Report.

Exempt Categories:

	<p>Category 1: Research conducted in established or commonly accepted educational settings, that specifically involves normal educational practices that are not likely to adversely impact students' opportunity to learn required educational content or the assessment of educators who provide instruction. This includes most research on regular and special education instructional strategies, and research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.</p>
x	<p>Category 2: Research that only includes interactions involving educational test (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: (i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; (ii) Any disclosure of the human subjects' responses outside</p>

	the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (iii) The information obtained is recorded by the investigator in such a manner that the identity of the humans subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 46.111(a)(7).
	Category 3: Research involving benign behavioral interventions in conjunction with the collection of information from an adult subject through verbal or written responses (including data entry) or audiovisual recording if the subject prospectively agrees to the intervention and information collection and at least one of the following criteria is met: (A) The information obtained is recorded by the investigator in such a manner that the identity of human subjects cannot be readily ascertained, directly or through identifiers linked to the subjects; (B) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (C) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can be readily ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 46.111(a)(7).
	Category 4: Secondary research for which consent is not required.
	Category 5: Research and demonstration projects that are conducted or supported by a Federal department or agency, or otherwise subject to the approval of department or agency heads, and that are designed to study, evaluate, improve, or otherwise examine public benefit or service programs, including procedures for obtaining benefits or services under those programs, possible changes in or alternatives to those programs or procedures, or possible changes in methods or levels of payment for benefits or services under those programs.
	Category 6: Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome foods without additives are consumed or (ii) if a food is consumed that contains a food ingredient at or below the level found to be safe, by the Food and Drug Administration or approved by the Environmental Protection Agency or the Food Safety and Inspection Service of the U.S. Department of Agriculture.
	Category 7: Storage or maintenance for secondary research for which broad consent is required: Storage or maintenance of identifiable private information or identifiable biospecimens for potential secondary research use if an IRB conducts a limited IRB review and makes the determinations required by 46.111(a)(8).
	Category 8: Secondary research for which broad consent is required: Research involving the use of identifiable private information or identifiable biospecimens for secondary research use, if the following criteria are met: (1) Broad consent for the storage, maintenance, and secondary research use of the identifiable private information or identifiable biospecimens was obtained in accordance with §46.116(a)(1) through (4), (a)(6), and (d); (2) Documentation of informed consent or waiver of documentation of consent was obtained in accordance with §46.117; and (3) An IRB conducts a limited IRB review and makes the determination required by §46.111(a)(7) and makes the determination that the research to be conducted is within the scope of the broad consent referenced in paragraph (d)(8)(i) of this section; and (iv) The investigator does not include returning individual research results to participants as part of the study plan. Note: This provision does not prevent an investigator from abiding by any legal requirements to return individual research results.

Ball State Specific Exempt Categories

	Category 9: Research involving publicly observable online behavior. Any online behavior that requires a person's permission to access is considered private and does not fall under this category. Information that cannot be accessed by the general population would also be considered private.
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Category 10: Research involving BSU students who are under 18 but have legal authority over their FERPA protected information. Only studies that fall into another exempt category except for sampling from BSU students who are under 18 can be considered exempt in this category.

Editorial Notes:

1. approved.
2. Please be aware of our updated guidance for COVID-19.

While your project does not require continuing review, it is the responsibility of the P.I. (and, if applicable, faculty supervisor) to inform the IRB if the procedures presented in this protocol are to be modified or if problems related to human research participants arise in connection with this project. **Any procedural modifications must be evaluated by the IRB before being implemented, as some modifications may change the review status of this project.** Please contact Sena Lim at (765)285-5034 or slim2@bsu.edu if you are unsure whether your proposed modification requires review or have any questions. Proposed modifications should be addressed in writing and submitted electronically to the IRBNet as a "Modification/Amendment" for review. Please reference your IRB protocol number 1548272-1 in any communication to the IRB regarding this project.

In the case of an adverse event and/or unanticipated problem, you will need to submit written documentation of the event to IRBNet under this protocol number and you will need to directly notify the Office of Research Integrity (<http://www.bsu.edu/irb>) **within 5 business days**. If you have questions, please contact Sena Lim at (765)285-5034 or slim2@bsu.edu.

Reminder: Even though your study is exempt from the relevant federal regulations of the Common Rule (45 CFR 46, subpart A), Ball State has elected to hold you accountable to these regulations to encourage best research practices. You and your research team are not exempt from ethical research practices and should therefore employ all protections for your participants and their data which are appropriate to your project.