Racism in Medicine and Science

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CERTIFICATE OF APPROVAL

Honors Thesis

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Abstract

The history of racism and prejudice in the United States is not limited to segregation, slavery, and discrimination. Medical and scientific racism continue to disproportionately affect Black and Indigenous People of Color (BIPOC). BIPOC have been used for scientific advancement without full disclosure of potential harm or adequate compensation. Scientists and medical providers have dehumanized minority individuals by disrespecting their autonomy and targeting vulnerable populations. This thesis consists of a literature review that surrounds the history of medical and scientific exploitation of people of color, ethical guidelines surrounding research, eugenics, and how assumptions affect the quality of care that minority groups receive, and results from new research are presented.

Introduction

This paper examines the history of medical and scientific racism towards Black and Indigenous People of Color (BIPOC) populations. This population is of interest because the United States (US) has a long history of cultural insensitivity and other issues in medical practices that have disproportionately affected BIPOC persons. As a result, contemporary BIPOC individuals have long term psychological effects and difficulty with trusting health officials-- including vaccinations.

Racism, prejudice, and discrimination against BIPOCs go beyond slurs, segregation, and pay inequalities. For purposes of this paper, the terms BIPOC and POC (people of color) will be used interchangeably to cover groups who identify as Black, Hispanic/ Latino, Asian, and Native American/ Indigenous. A more recent exposure of biases in medical treatment toward women and men of color has surfaced and may be a shock to many that have not experienced medical racism. In the article, “Birthing While Black" anthropologist Dana-Ain Davis defines medical racism as “the ideas and practices that perpetuate racial hierarchies and compromise one’s health or facilitate vulnerability to premature illness or death” (List, 2020: 36). While race and ethnicity may make some groups more prone to various medical issues than others, the line between medical treatment for BIPOC populations based on outdated assumptions and true science may be thin.

To address the topic of racism in medicine and science, this paper first provides an overview of the literature related to this topic. Second, quantitative data collected using a survey developed by the author is presented and analyzed. Lastly, the findings and future directions for this line of research as well as the policy implications to improve equality within healthcare that deal with the issue of racism in medicine and science are discussed.

Health Inequalities

The widespread assumptions surrounding the inherent difference between BIPOC health and the health of white individuals does not account for all health influences. Health disparities are not entirely due to biological differences between the groups, but too many economic, social, and environmental factors. Areas in which the population is majority BIPOC tend to receive inadequate healthcare, are negatively affected by political policies, and tend to be more stressed (Bailey et al., 2017) -- each of these issues affect health.

Socioeconomic status (SES) encompasses income levels, educational attainment, and overall social status; SES is positively associated with better health outcomes (Baker, 2014). In a study that analyzed data from births from 2009-2017, researchers Jackson and Testa (2020) compared race/ethnicity, SES, and infant health. The researchers focused on low income parents that received The Special Supplemental Nutrition Program for Women, Infant, and Children (WIC) which provides aid for items such as food and formula while supplying nutritional information to parents. To be considered for the program, applicants must meet federal poverty guidelines that vary by household size. WIC has been found to have better health and birth outcomes for mothers with low SES. The researched health outcomes showed that Black mothers were at a significantly higher risk of delivering infants with health problems, Hispanic mothers were found to be at second highest risk, and White mothers were least likely of the three groups to have infants with concerning health conditions (Jackson & Testa, 2020). When mothers were provided with food assistance and nutritional facts through WIC, data has shown that there were less adverse infant health outcomes in Black and Hispanic families (Jackson & Testa, 2020).

Health programs as well as an extension of health education has been proven to decrease the gap in health disparities that exist between BIPOCs and Whites.

Even when SES are equal between African Americans and whites, African Americans with higher SES continue to report unsatisfactory care.

The differences between white and BIPOC health as it relates to non-biological factors is the structural aspect of racism. Structural racism includes interconnected systems, whose "linkages are historically rooted and culturally reinforced" (Bailey et al., 2017). Racism affects the mortality rate of BIPOC because of gaps in healthcare. Although all ethnic and racial groups can contract various diseases, the prevalence and treatment of disease and illness varies greatly between racial groups (Marcellin et al., 2019). To better understand the observed racial disparities in health, one must first understand the history of medical distrust between whites and racial/ethnic minorities in the United States.

A History of Distrust

Doctors, scientists, and law-makers have historically impeded the autonomy of Black and Indigenous People of Color (BIPOC). For example, the reproductive rights of men and women of color have been decided for them through legislation and health providers' suggestions (Marcellin et al., 2019). Such racism and mistreatment contributed to the disdain and mistrust of BIPOC people toward healthcare systems and scientific studies. Additionally, the cultural memories of medical racism from the past continues to affect modern generations of racial and ethnic minorities.

Cultural memory is an amalgamation of oral stories told, written texts, and histories that surround experiences of a specific cultural group (Assmann, 2011). Cultural memory has influenced how groups remember, relate to, and address future situations. The Tuskegee Syphilis Experiments are an example of a cultural memory that African Americans, both past and present, share.

"The Tuskegee Study of Untreated Syphilis in the Negro Male" examined the effects of syphilis at the expense of African American men (CDC, 2020). African American men were studied from 1932-1972 without informed consent and misdiagnosed with "bad blood" rather than syphilis. In 1945, penicillin was found to be successful for treating syphilis, but the subjects of the study were not disclosed this information and not given the proper available treatment. In 1969, the US government's Center for Disease Control (CDC) that was conducting the research, claimed that the study was necessary and supported the continuation of the experiment. It was not until 1972 that backlash in the media influenced the conclusion of the study.

The Tuskegee Experiments may have been terminated nearly fifty years ago, but the effects are still evident in the Black community. Studies have shown that Black Americans share a cultural memory of the unethical experiments, which has contributed to the mistrust of the medical and scientific community. Jaiswal and Halkitis (2019) consider the Tuskegee Experiments a "catalyst" of medical mistrust in the Black community. Medical mistrust in groups that have been historically mistreated contributes to trends of health disparities (Jaiswal & Halkitis, 2019). A study by Arnett et al. (2016) found that African American men were less likely than whites to utilize a primary care physician but were more likely to use the Emergency Department when needed. The results of the study imply that, due to medical mistrust, African Americans tend to avoid primary care visits but will resort to medical help in the case of a

presumed emergency. Medical mistrust stemming from the Tuskegee Syphilis Experiment and other incidents of medical and scientific racism, influences how reluctant individuals can be to seek medical help-- which affect their own health and that of others.

Biases Affect Quality of Treatment

We can see how the history of distrust in the medical and scientific community continues to perpetuate racial biases that affect differences in the quality of treatment and healthcare today. A study in 2016 by Hoffman, Trawalter, Axt, and Oliver examined white people's biases toward black patients. The participants were residents, medical students, and individuals outside of the healthcare field. The first portion of the study prompted participants to rate how painful a given scenario is and to rate the biological differences between black and white people. Statements on biological differences expressed by the white participants included:

1) Blacks age more slowly than whites; 2) Blacks' nerve endings are less sensitive than whites'; 3) Black people's blood coagulates more quickly than whites'; 4) Whites have larger brains than blacks; 5) Whites are less susceptible to heart disease than Blacks*; 6) Blacks are less likely to contract spinal cord diseases*; 7) Whites have a better sense of hearing compared with Blacks, Blacks' skin is thicker than whites'; 8) Blacks have denser, stronger bones than whites*; 9) Blacks have a more sensitive sense of smell than whites; 10) Whites have a more efficient respiratory system than blacks Black couples are significantly more fertile than white couples; 11) Whites are less likely to have a stroke than blacks*; 12) Blacks are better at detecting movement than whites; and 13) Blacks have stronger immune systems than whites (Hoffman et al, 2016).

Many of these statements imply that Black people heal faster than white people and that Black people feel less pain. The factual statements are denoted by asterisks. On average, lay people

agreed that many of the false beliefs statements are true, followed by first and second year medical students.

In the second part of the Hoffman study, only first, second, and third year medical students and residents were questioned. There were 15 statements presented, 11 of which were false beliefs surrounding biological and health differences between Black and white people. A mock medical scenario was presented and the participants were then asked how they would go about treating the patient. After controlling for various variables, the authors found that there was a positive correlation in greater racial bias in pain ratings was associated with greater racial bias in the accuracy of treatment recommendation (Hoffman et al., 2016). "About 50% reported that at least one of the false belief items was possibly, probably, or definitely true. These percentages are noticeably lower compared with those in study 1 (50% vs. 73%); however, given this sample (medical students and residents), the percentages for false beliefs are surprisingly high" (Hoffman et al., 2016). Overall, the study's results show how medical provider's biases can influence how seriously they tend to patients' concerns and affect the treatment provided.

Medical professionals' biases can quickly turn into negligence; negligence can then result in death. An example of the effects of medical negligence can be seen by closely examining the rate of infant mortality in the United States, which is highest among Blacks. In fact, the contemporary infant mortality gap between white and Black infants is even greater than it was during slavery (Owens and Fett, 2019). Oftentimes, these deaths have been accredited to higher poverty rates, lower educational attainment, and lower overall maternal health-- which may be true in many cases, but a 2019 study examined another aspect of infant death rates: the doctors. The 2019 study found that Black infants were less likely to die when treated by Black doctors as opposed to white doctors. Black mothers are 8 times more likely to die during pregnancy and

delivery than white mothers (Owens & Fett, 2019). Davis (2019) attributes overall negative pregnancy and birth experiences that Black women face to obstetric racism. Obstetric racism is defined as a mix of gender-based violence, obstetric violence, and medical racism (Davis, 2019). Davis pleas for American medicine to be decolonized to prevent future deaths for people of color (Davis, 2019). A decolonization of American medicine means that medical providers must develop a greater sense of cultural sensitivity, must abandon assumptions, and acknowledge BIPOC's health concerns.

Racism trickles into so many aspects of life because of its systemic nature. Racism exists at interpersonal and structural levels, thus the need for overall dismantling of racism is absolutely dire (Jaiswal, 2019). The process of dismantling racism is no easy feat because it is so complex. The first step to addressing medical and scientific racism is to acknowledge its history, current existence, and the long-term effects that it has had on various communities.

Women of Color Used As Guinea Pigs

One such community that has been disadvantaged include Black, Indigenous, and Latinx women that have been used as test subjects for risky experiments. Women of color are incommensurate victims of medical and scientific biases because of their ability to reproduce and their undervalued status in society. While some minority women voluntarily participated but were not adequately disclosed informed of the true nature of the experiments, many others were involuntarily recruited to take part in these unethical medical studies and procedures.

The Immortal Life of Henrietta Lacks recounts Henrietta Lack's involuntary contribution to science (Skloot, 2011). Henrietta Lacks was an African American woman that died in 1951 from cervical cancer. Lacks' doctor, Dr. TeLide, offered free services-- although he did not charge a fee, care came in the cost of undisclosed research on his patients (McCullough, 2020;

Skloot, 2011). After her death, researchers did not want her identity disclosed to the public and decided to name her biological samples "HeLa cells." Lacks' samples were obtained shortly after her death from various organs. Lacks' cells were used without prior consent and incorporated into various vaccines and pharmaceuticals. None of Lacks' five children ever received compensation on her behalf. Utilizing members of vulnerable minority groups is not justified by scientific advancement, especially when permission was not granted and compensation is not provided. Unfortunately, women of color continue to be failed and used as scientific guinea pigs.

A predecessor to Henrietta Lacks' mistreatment was the unjust experimentation of enslaved women. Enslaved women had a major impact on today's gynecology. The notorious James Marian Sims performed numerous surgeries on enslaved African American women without anesthesia. Sims is credited for his findings in gynecology, but he performed experimental surgeries without knowledge of how the operations could affect the women. Sims deemed vaginal operations as minimally invasive, thus anesthesia was not necessitated-- however, upper class white women were given anesthetics as he considered them most vulnerable to pain. This opinion reflects stereotypes that Black individuals feel less pain than Whites that still resonates today. Sims treated many Black patients, so some scholars argue that he was not racist, but will admit that his own reporting is biased as he seems to shield many details of his practices (Sartin, 2004). Sims' contribution to American medicine therefore surpasses his questionable practices and his attitude toward Black women mirror stereotypes that exist today.

The exploitation of BIPOC women for medical and scientific reasons still continues today. As recently as 2006-2010, approximately 140 of the women in California prisons were sterilized-- over 50% were women of color (Whatcott, 2018). The rates of women of color in

prison are notably higher than white women-- at a ratio of 6 Black women to one White woman and 1.8 Hispanic women to one White woman in the year 2000 (Mauer, 2013). The method of sterilization in the California prison was tubal ligation, which is a medical procedure that burns/ cuts the fallopian tubes to permanently prevent fertilization, thus rendering patients infertile (Sung & Abramovitz, 2020). Advocates questioned if the tubal ligations were decided by the patients and if incarcerated people could make any uncoerced decisions.

News of the sterilizations awakened the concern of many, and an audit was conducted in 2013. Auditors found numerous flaws within the informed consent process including the fact that medical and prison officials neglected to take proper steps to ensure that the patient was protected and thoroughly informed-- the officials also defied the law by avoiding committee approval. Other failures included the lack of a signature showing that the patient was mentally competent and understood the long-term effects of the procedure. Evidence was also found that medical or prison officials had forged the date intended to demonstrate that the necessary waiting period had been completed before performing the surgery. The report also observes another deficiency: in all but one single case, medical and prison officials did not follow a state law that requires approval from both a state prison medical committee and a committee at the federal receiver's office overseeing state medical care (Whatcott, 2018). The blatant and immoral disregard and mistreatment of BIPOC women is a current, dire issue that has added to mistrust in healthcare providers and healthcare agencies.

Targets of Eugenics

The practice of sterilizing BIPOC women is rooted in the scientific belief in, and practice of, eugenics. Eugenics is defined as "the science that deals with all influences that improve the

inborn qualities of a race" (Galton, 1904). Laws in the United States in the early to mid-1900s promoted sterilization of men and women, especially individuals of color, and the movement was created with the intention of controlling reproduction to impose restrictions on future genetics (Anamoly, 2014). Many women had been either forcibly sterilized or underwent the procedure without fully knowing about the permanence of sterilization.

The early laws enforced eugenics by preventing reproduction from minority groups, particularly targeting Native American, African American, and Puerto Rican women (Nurridin et al., 2020). The idea of eugenics originated from the writing of Sir Francis Galton who advocated for controlling reproduction so that only offspring with desirable characteristics are born, thus improving the species (O'Brien, 2011). The practice of eugenics in the United States began to prevent individuals deemed mentally and intellectually weak from reproduction through forced sterilization and institutionalization (O'Brien, 2011). Birth control trials in the early 1900s on Puerto Rican women-- many of whom experienced side effects from sterilization to death-- exemplify eugenics. By 1953, 17% of Puerto Rican women had been sterilized to control the rising population and prevent undesirable reproduction (Lopez, 2008).

Similarly, in 2020, shocking news surfaced that immigrant women at Immigration and Customs Enforcement (ICE) detention centers have received hysterectomies (Lenzer, 2020). There are ongoing investigations about the consent process and if the hysterectomies were either medically necessary or requested by the female detainees. The medical director of the ICE Health Service Corps, Aida Rivera, has denied that the procedures were done without consent and maintains that each scenario had approval from clinical authority. Detainees, however, argue that many other detainees underwent the operation without full disclosure. The British Medical Journal reported the detainee's account of the operations, "One detainee at the Irwin center said

she knew of five women who had been subjected to hysterectomies who appeared confused about what had been done to them or why the operations were performed" (Lenzer, 2020: 1). The contrasting recollections of hysterectomies in ICE camps proves that there is an urgent need for further investigation because such unethical procedures bring into question *who* is really protected from medical and scientific injustices.

Ethical Limitations to Research

Despite the continued practice of eugenics today, a number of policies have been enacted over the years aimed at reducing racism in medicine and science. For instance, prior to the introduction of the National Research Act in 1974 and the Institutional Review Board (IRB) in 1974, many studies were conducted that would not be considered as ethical research today. The National Research Act set guidelines for how conducting ethical research experiments on human subjects must be approached (United States Department of Health and Human Services, n.d). In this act, the Belmont Report was created to include the principles of respect for persons, beneficence, and justice. The respect for persons principle specifies that subjects must be mentally capable of advocating for themselves and must be briefed on the purposes and conditions of the study. Researchers must be transparent about what participants will be exposed to and the goal of the study. Following the principle of beneficence ensures that participants will not be harmed. Researchers cannot physically harm or traumatize subjects; the goal is to avoid harm and maximize benefits for the researched subjects. When studying a vulnerable group such as children, the study would be accepted if the potential benefits outweigh the associated harm or risk factor. Finally, the principle of justice protects people from vulnerable racial and ethnic populations "the selection of research subjects needs to be scrutinized in order to determine

whether some classes (e.g., welfare patients, particular racial and ethnic minorities, or persons confined to institutions) are being systematically selected simply because of their easy availability, their compromised position, or their manipulability, rather than for reasons directly related to the problem being studied" (Belmont Report, 1979). The principle of justice restricts studies on groups that can be manipulated due to their lack of resources or mental capacity in cases of the intellectually disabled; if studies are done on these populations, there must be an intention to benefit the group through the research. Still, research on people of color in the United States before and after 1974 continues to harm, deceive, and disrespect BIPOC participants.

The Institutional Review Board (IRB) serves as an ethics committee for research throughout the United States and is federally funded. The IRB is required when doing research with human subjects and has many guidelines. Federal regulations for the IRB specify requirements for members and expectations for members to uphold. An IRB must have at minimum five members-- one must have a scientific background, one must not have a scientific background, and another must be unaffiliated. All members must have familiarity with laws and the goal to protect potential research subjects from harm. Individuals on the ethics committee are able to approve or deny proposed projects; members have to be updated should any changes come about and can terminate a study if researchers do not comply. The IRB's guidelines attempt to promote diversity within the membership in order to prevent biases. The various levels of oversight that is required by the IRB should, in theory, protect BIPOCs as they are a historically vulnerable population.

Current sentiments

The current global pandemic, COVID-19, hit Black and Brown neighborhoods hard. The virus, COVID-19, is a new coronavirus caused by SaRS-CoV-2; COVID-19 is labeled as a highly contagious respiratory disease that was discovered in 2019 (Center for Disease Control, 2019). Moore et al. (2020), reported that 33 states were considered COVID-19 hotspots from February 2020 to June 2020; of those states, the Latinos made up the largest group of ethnic minorities affected by COVID-19, followed by African Americans, American Indian/ Native Alaskan, Asian, and Native Hawaiian/ Pacific Islander (Moore et al, 2020; 1122). Hispanic communities made up three quarters of the hotspots with about 3.5 million inhabitants. Comparably, an estimated 2 million African Americans resided in hotspots; both groups were overrepresented in COVID-19 related hospitalizations and deaths (Moore et al., 2020; 1123). Areas where residents lived at or below the poverty line already had finite resources prior to the outbreak of COVID-19. The mortality rate for Black, Latino, and Indigenous groups is on average 3 times higher than the mortality rate of Caucasian groups (Schmidt et al., 2020). The Supreme Court contends that prioritizing healthcare for certain racial groups, even the vulnerable populations, is unethical. Even though BIPOCs continue to be equitably affected by the COVID-19 virus, vaccines are not deemed of utmost importance for these groups.

A recent study by Bogart et al (2020) surveyed African Americans who are HIV positive. The questionnaire surrounded how COVID has personally affected their lives from homelessness to loss of jobs, if they have been tested for COVID, and if they trust the government's involvement with COVID. The researchers found that 97% of the 101 participants had at least one mistrust recorded. Overall, most participants admitted to having the least amount of trust in government officials and their transparency about COVID and their dedication to African American citizens.

There are varying feelings toward the COVID-19 vaccine among Americans. However, BIPOC individuals' skepticism toward the vaccine are separable from the views of anti-vaxxers. Anti-vaxxers believe that vaccines are harmful and lead to various disorders, despite the lack of causal conclusions from scientists. BIPOCs with concerns surrounding the long-term effects of the vaccination must be addressed respectfully and not downplayed as a conspiracy theory (Razai et al 2010). The present study was created to grasp BIPOC's views of healthcare, their knowledge of past injustices, their credence, the COVID-19 vaccine, and how it can be compared to the opinions of non-BIPOC counterparts.

DATA AND METHODS

Participants

The present study focuses on data collected from friends/strangers of the author using FACEBOOK to examine racial differences in attitudes towards trust in the American healthcare system. A link to the Qualtrics survey was posted on Facebook for participants to voluntarily complete. The participants were selected by emailing, snowball sampling, and through social media. The survey began with two qualifying questions to make sure all participants were at least 18 years old and reside in the United States. Participants that were under age 18, did not reside in the United States, or did not answer all 37 survey questions were excluded from the analysis. The final analytical sample included 38 adult respondents.

Measures

The first dependent variable is *Healthcare Distrust*. This measure is a five-item index with scores ranging from 5 to 25 and is based on the Revised Health Care Distrust Scale (Shea et al., 2008). This scale's statements are focused on the healthcare system's treatment toward patients. Participants were prompted to respond to statements using a 5-point Likert scale ranging from Strongly Disagree (1) to Strongly Agree (5).

The second dependent variable is *Medical Distrust*. This measure is a nine-item index with scores ranging from 5 to 45 and is based on the Medical Distrust Scale (Rose et al., 2007). This portion also had statements about the health care system, its confidentiality, and the presumed integrity of the system. The answers ranged from Strongly Disagree (1) to Strongly Agree (5).

The independent variable is *Race*, which is a self-reported measure that categorizes respondents that identified as *Black, Afro-Caribbean, Asian, White, Hispanic, Multiracial, or Some-Other Race*.

I developed 13 questions that encompassed participants' views on the COVID vaccine, their personal experience with medical providers, and their knowledge of the Tuskegee Experiments and Henrietta Lacks. The questions in this portion of the survey were created by the author. The purpose of this selection is to determine if there is a relationship between participants' race and these variables presented.

Sociodemographic characteristics include the respondent's: *Gender* (1 = female, 0 = male); *Age* (1) 18-25, 2) 26-30, 3) 31-40, 4) 41-50, 5) 51-60, 6) 61-70, 7) 70+), ; *Income* (1) <$25,000, 2) $25,000-$44,999, 3) $45,000,- $54,999, 4) $55,000-$64,999, 5) $65,000-$74,000, 6) $75,000-$90,000, and 7) >$90,000); and *Education* (less than high school, high

school graduate, some college, Associate degree, Bachelor degree, Master's degree, and Doctorate or professional degree).

Qualitative measure. The final question of the survey was open-ended and asked respondents "In your opinion, what can be done to strengthen people's trust in America's healthcare system?" Responses to this question were used as a measure for people's trust in the medical system.

Results

The results of the descriptive analyses of the sample means and proportions for the analytic sample of 38 participants is presented in Table 1. The results show that 9 respondents self-identified as Black, 1 Afro-Caribbean, 2 Asian, 18 Hispanic, 3 White, 4 Multiracial, and 1 Some-Other Race. Approximately 61% of the sample were female and the average respondent was about 42 years old. Most of the respondents (60%) had an income of less than $55,000 per year but their educational attainment greatly varied with 18% being high school graduates, 5% having some college education, 24% have Bachelor's degrees, and 21% have Master's degrees.

The respondents' total responses to familiarity with the Tuskegee Experiments showed that 31.6% did not have prior knowledge while 52.6% did. The responses for familiarity with Henrietta Lacks were 39.4% unfamiliar and while 34.2% were familiar. In response to receiving adequate care from doctors with the same racial/ ethnic background 15% disagreed while 68.5% agreed with the statement. The answers to the previous state contrast with the following statement regarding receiving adequate care from doctors with different racial/ ethnic backgrounds an increase in disagreement (23.7%) and a slight drop in agreement (63.2%).

Table 2 presents the results of the analyses of a series of cross-tabulations comparing racial/ethnic differences for mistrust of the healthcare system. Table 2A examines responses to the statement “I am willing to take the COVID-19 vaccine”.

Table 2B examines responses to the statement “I am familiar with Henrietta Lacks.” Table 2C displays the results from the prompt “I have received adequate care from doctors with different racial/ ethnic background as me.” Table 2D reveals responses by racial and ethnic background to “I trust government health agencies” which is succeeded by the next table (2E) “I have felt discriminated against by a healthcare worker because of my gender.” The final two presented tables provide results from the statements “I am familiar with the Tuskegee Experiments” (table 2F) and “I have felt discriminated against by a healthcare worker because of my gender” (Table 2G) Table 2G cross analyzes gender as opposed to race. The responses to each of pertinent statements are assessed in the upcoming section.

The response to the statement “I am familiar with the Tuskegee Experiments" varied by respondents’ racial backgrounds. The total responses for this statement include a majority of African American respondents who were familiar with the experiments (88.9%) as compared to many Caucasian who were not (66.7%). The disparity between the two groups is mirrored in the responses to the following statement “I am familiar with Henrietta Lacks.” Over half of African American participants answered that they were aware (66.7%), all Afro-Caribbean participants had prior knowledge of Henrietta Lacks, and more than half of Caucasian respondents did not have prior knowledge of the topic (66.7%). A clear disparity exists between the participants’ willingness to receive the COVID-19 vaccine-- a vast amount of African Americans disagreed with the statement “I am willing to receive the COVID vaccine” (55.7%) compared to the overwhelming majority of White respondents that agreed to the statement (66.7%). Hispanic

respondents' answers to the aforementioned statements were divided between agreeing and disagreeing (22.3% and 61.1%, respectively). For prompt number 30 that stated “I have felt discriminated against by a healthcare worker (doctor, nurse, etc.) because of my gender,” Caucasians felt most discriminated by gender (66.7%), followed by African Americans (33.3%), Hispanics (27.8%), while Afro-Caribbean’s, multiracial, and Asian respondents unanimously claimed to have not experienced gender-motivated discrimination. When this statement is assessed by gender, it was found that females reported more gender-motivated discrimination (30.4%) while 20.5% of males reported the same.

The following statement, “I have felt discriminated against by a healthcare worker (doctor, nurse, etc.) because of my racial/ ethnic background,” elicited the following responses: 33.3% of White respondents agreed to the statement, 22.3% of Hispanic respondents agreed, and 44.4% of African American respondents also agreed. African Americans make up the largest percentage of respondents that admit to feeling discriminated against because of their race in comparison to a total of survey responses that agreed with the statement at 29%.

Discussion

The current study utilized data from a small sample of individuals from varying backgrounds. While the answers that participants provided gave insight into the topic of how biased history affects their current trust in the healthcare system, a large sample would be more beneficial. Responses to the concluding, open ended question “In your opinion, what can be done to strengthen people’s trust in the healthcare system?” often paralleled one another, regardless of age and racial background.

Survey respondents' concerns surrounding healthcare followed similar trends-- affordability, feelings of insecurity with doctors, lack of transparency, and mistrust in the government. A majority of responses from all age groups centered on the need for honesty from healthcare providers, the government, and media. One respondent in particular stated, "It's not a question of what can be done, it's are they willing to do it? Full transparency from the government to the general public regarding our healthcare system would be a start. Then discussing what changes are in order for a more balanced system would aid in solving the issue at hand."

Also, learning that minority patients lack trust in the medical system is not a new revelation-- many are already aware or can assume that BIPOCs struggle in this area. Thus, changes must be made to mend the relationship between BIPOCs and healthcare and science for the good of their health.

A survey was a method of assessing qualitative data pertaining to the issue. There is a need for further studies on the topic, specifically relating to COVID and the COVID-19 vaccine. Focus groups are a probable method of learning about subjects, their specific concerns, and their past experiences. Furthermore, possible confounding variables that were not addressed in this study should be attended to in future studies-- discrimination based on age, abilities, and sexual orientation. A focus group allows for more in-depth studying of individuals with overlapping concerns. We are aware that mistrust is existent, but a thorough plan needs to be constructed to prevent greater health disparities between groups. An additional approach to reducing health disparities and strengthening trust is community-based participatory research that relays vital health information to members of underserved communities, allows individuals to voice their concerns, creates a connection between policy makers, researchers, and community members,

and brings people closer to health equality (Thompson et al., 2016). While the tragic histories are in the past, the memory has not faded and current biases still stand as a threat—giving a voice to those that have been silenced is a step in the right direction.

Table 1. Descriptive Statistics of Sample Means

Variable	N=38		Variable Range	
	Mean/ %	SD	Min	Max
Race				
Black	0.24	0.43	0	1
Afro-Caribbean	0.03	0.16	0	1
Asian	0.05	.023	0	1
White	0.08	0.27	0	1
Hispanic	0.47	0.51	0	1
Multiracial	0.11	0.31	0	1
Other	0.03	0.16	0	1
Gender				
Female	0.61	0.50	0	1
Male	0.39	0.50	0	1
Age	3.71	1.72	0	7
Income				
< $25,000	0.11	0.31	0	1
$25,000-$44,999	0.24	0.43	0	1
$45,000,- $54,999	0.26	0.45	0	1
$55,000-$64,999	0.00	0.00	0	1
$65,000- $74,000	0.08	0.27	0	1
$75,000-$90,000	0.08	0.27	0	1

>$90,000	0.21	0.41	0	1
Education				
Less than high school	0.00	0.00	0	1
Some high school	0.03	0.16	0	1
High school Diploma or GED	0.18	0.39	0	1
Some College	0.24	0.43	0	1
Associate Degree	0.05	0.23	0	1
Bachelor's Degree	0.24	0.43	0	1
Master's Degree	0.21	0.41	0	1
Doctorate or Professional Degree	0.03	0.16	0	1

Note: Some columns do not total 100 due to rounding error

Table 1. Continued

Variable	N=38		Variable Range	
	Mean/ %	SD	Min	Max
Healthcare Mistrust	13.42	4.82	5	25
Medical Mistrust	26.32	7.35	12	45
Tuskegee	3.47	1.70	1	5
Henrietta	2.95	1.59	1	5
Same-Race Doctor	3.68	1.09	1	5
Other-Race Doctor	3.58	1.20	1	5
Respect	4.08	1.00	1	5
Gender Discrimination	2.47	1.31	1	5
Race Discrimination	2.66	1.26	1	5
COVID willing	3.16	1.75	1	5
COVID aware	3.53	1.43	1	5
COVID trust	2.66	1.51	1	5
Trust government	2.58	1.37	1	5
Government health	2.29	1.21	1	5
Government transparency	2.26	1.29	1	5

Note: Some columns do not total 100 due to rounding error

Table 2. Cross-Tabulation Tables

Table 2A

		Race/Ethnicity								
		Total	Black	Afro Caribbean	Asian	White	Hispanic	Native American	Multiracial	Other
I am willing to take a COVID-19 vaccine.	Strongly disagree	31.60%	55.60%	100.00%	50.00%	0.00%	16.70%	0.00%	25.00%	100.00%
	Somewhat disagree	7.90%	0.00%	0.00%	0.00%	33.30%	5.60%	0.00%	25.00%	0.00%
	Neither agree nor disagree	13.20%	22.20%	0.00%	0.00%	0.00%	16.70%	0.00%	0.00%	0.00%
	Somewhat agree	7.90%	11.10%	0.00%	0.00%	0.00%	11.10%	0.00%	0.00%	0.00%
	Strongly agree	39.50%	11.10%	0.00%	50.00%	66.70%	50.00%	0.00%	50.00%	0.00%

Table 2B

		Race/Ethnicity								
		Total	Black	Afro Caribbean	Asian	White	Hispanic	Native American	Multiracial	Other
I am familiar with Henrietta Lacks.	Strongly disagree	28.90%	0.00%	0.00%	50.00%	66.70%	38.90%	0.00%	25.00%	0.00%
	Somewhat disagree	10.50%	0.00%	0.00%	0.00%	0.00%	16.70%	0.00%	0.00%	100.00%
	Neither agree nor disagree	26.30%	33.30%	0.00%	50.00%	0.00%	33.30%	0.00%	0.00%	0.00%
	Somewhat agree	5.30%	0.00%	100.00%	0.00%	33.30%	0.00%	0.00%	0.00%	0.00%
	Strongly agree	28.90%	66.70%	0.00%	0.00%	0.00%	11.10%	0.00%	75.00%	0.00%

Table 2C

		Race/Ethnicity								
		Total	Black	Afro Caribbean	Asian	White	Hispanic	Native American	Multiracial	Other
I have received adequate care from doctors with different racial/ ethnic background as me.	Strongly disagree	5.30%	11.10%	0.00%	0.00%	0.00%	5.60%	0.00%	0.00%	0.00%
	Somewhat disagree	18.40%	44.40%	0.00%	0.00%	33.30%	5.60%	0.00%	0.00%	100.00%
	Neither agree nor disagree	13.20%	33.30%	0.00%	0.00%	0.00%	5.60%	0.00%	25.00%	0.00%
	Somewhat agree	39.50%	11.10%	100.00%	50.00%	0.00%	50.00%	0.00%	75.00%	0.00%
	Strongly agree	23.70%	0.00%	0.00%	50.00%	66.70%	33.30%	0.00%	0.00%	0.00%

Table 2D

		Race/Ethnicity								
		Total	Black	Afro Caribbean	Asian	White	Hispanic	Native American	Multiracial	Other
I trust government healthcare agencies.	Strongly disagree	31.60%	55.60%	100.00%	0.00%	0.00%	16.70%	0.00%	50.00%	100.00%
	Somewhat disagree	15.80%	0.00%	0.00%	50.00%	33.30%	22.20%	0.00%	0.00%	0.00%
	Neither agree nor disagree	26.30%	44.40%	0.00%	0.00%	0.00%	27.80%	0.00%	25.00%	0.00%
	Somewhat agree	15.80%	0.00%	0.00%	50.00%	66.70%	11.10%	0.00%	25.00%	0.00%
	Strongly agree	10.50%	0.00%	0.00%	0.00%	0.00%	22.20%	0.00%	0.00%	0.00%

Table 2E

		Race/Ethnicity								
		Total	Black	Afro Caribbean	Asian	White	Hispanic	Native American	Multiracial	Other
I have felt discriminated against by a healthcare worker (doctor, nurse, etc.) because of my gender.	Strongly disagree	34.20%	11.10%	100.00%	100.00%	33.30%	38.90%	0.00%	25.00%	0.00%
	Somewhat disagree	15.80%	11.10%	0.00%	0.00%	0.00%	16.70%	0.00%	50.00%	0.00%
	Neither agree nor disagree	23.70%	44.40%	0.00%	0.00%	0.00%	16.70%	0.00%	25.00%	100.00%
	Somewhat agree	21.10%	22.20%	0.00%	0.00%	66.70%	22.20%	0.00%	0.00%	0.00%
	Strongly agree	5.30%	11.10%	0.00%	0.00%	0.00%	5.60%	0.00%	0.00%	0.00%

Table 2F

		Race/Ethnicity								
		Total	Black	Afro Caribbean	Asian	White	Hispanic	Native American	Multiracial	Other
I am familiar with the Tuskegee Experiments.	Strongly disagree	23.70%	0.00%	0.00%	50.00%	66.70%	33.30%	0.00%	0.00%	0.00%
	Somewhat disagree	7.90%	0.00%	0.00%	0.00%	0.00%	16.70%	0.00%	0.00%	0.00%
	Neither agree nor disagree	15.80%	11.10%	0.00%	0.00%	0.00%	27.80%	0.00%	0.00%	0.00%
	Somewhat agree	2.60%	0.00%	0.00%	0.00%	33.30%	0.00%	0.00%	0.00%	0.00%
	Strongly agree	50.00%	88.90%	100.00%	50.00%	0.00%	22.20%	0.00%	100.00%	100.00%

Table 2G

I have felt discriminated against by a healthcare worker (doctor, nurse, etc.) because of my gender.

	Biological Sex		
	Total	Male	Female
Strongly disagree	23.70%	0.00%	0.00%
Somewhat disagree	7.90%	0.00%	0.00%
Neither agree nor disagree	15.80%	11.10%	0.00%
Somewhat agree	2.60%	0.00%	0.00%
Strongly agree	50.00%	88.90%	100.00%

Appendix

Please read each of the following questions and statements carefully and, to the best of your ability, provide the most honest and appropriate answer.

Qualifiers:

I am at least 18 years old.
Yes
No

I reside in the United States.
Yes
No

Demographics:

What is your current age in years?
1. 18-25
2. 26-30
3. 31-40
4. 41-50
5. 51-60
6. 61-70

7. 70+

With which racial and ethnic groups do you identify?

African American/ Non-Hispanic Black
Afro-Caribbean
Asian/Pacific Islander
Caucasian/Non-Hispanic White
Hispanic/Latino
Native American
Multiracial
Other

3. What is your biological sex?

Male
Female
Non Binary

4. What is your estimated yearly income?

1. < $25,000,
2. $25,000-$44,999
3. $45, 000, - $54,999
4. $55,000-$64,999

5. $65,000- $74,000
6. $75,000-$90,000
7. >$90,000

5. What is your highest level of educational attainment?
   1. Less than high school
   2. Some high school
   3. High school Diploma or GED
   4. Some College
   5. Associate Degree
   6. Bachelor's Degree
   7. Master's Degree
   8. Doctorate or Professional Degree

Please indicate the extent to which you agree with the following statements:

6. The Health Care system does its best to make patients' health better.
   1. Strongly disagree
   2. Somewhat disagree
   3. Neither disagree nor agree
   4. Somewhat agree
   5. Strongly agree

7. The Health Care System covers up its mistakes.

1. Strongly disagree
2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

8. Patients receive high quality medical care from the Health Care System.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

9. The Health Care System makes too many mistakes.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

10. The Health Care System puts making money above patients' needs.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree

5. Strongly agree

11. The Health Care System gives excellent medical care.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

12. Patients get the same medical treatment from the Health Care System, no matter what the patient's race or ethnicity.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

13. The Health Care System lies to make money.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

14. The Health Care System experiments on patients without them knowing.
    1. Strongly disagree

2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

Please indicate the extent to which you agree with the following statements:

15. Medical experiments can be done on me without my knowing about it.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

16. My medical records are kept private.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

17. People die every day because of mistakes by the health care system.
    1. Strongly disagree
    2. Somewhat disagree

3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

18. When they take my blood, they do tests they don't tell me about.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

19. If a mistake were made in my health care, the healthcare system would try to hide it from me.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

20. People can get access to my medical records without my approval.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

21. The health care system cares more about holding costs down than it does about doing what is needed for my health.

1. Strongly disagree
2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

22. I receive high-quality medical care from the health care system.

1. Strongly disagree
2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

23. The health care system puts my medical needs above all other considerations when treating my medical problems.

1. Strongly disagree
2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

24. Some medicines have things in them that they don't tell you about.

1. Strongly disagree
2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

Please indicate the extent to which you agree with the following statements:

25. I am familiar with the Tuskegee Experiments

1. Strongly disagree
2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

26. I am familiar with Henrietta Lacks

1. Strongly disagree
2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

27. I have received adequate care from doctors with the same racial/ ethnic background as me.

1. Strongly disagree
2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

28. I have received adequate care from doctors with different racial/ ethnic background as me.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

29. I have been treated with respect most times I visit a healthcare provider.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

30. I have felt discriminated against by a healthcare worker (doctor, nurse, etc.) because of my gender.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree

4. Somewhat agree
5. Strongly agree

31. I have felt discriminated against by a healthcare worker (doctor, nurse, etc.) because of my racial/ethnic background.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

32. I am willing to take a COVID vaccine.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

33. I am aware of the contents of the COVID vaccine.
    1. Strongly disagree
    2. Somewhat disagree

3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

34. I trust that the reported contents of the COVID vaccine are true.
1. Strongly disagree
2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

35. I trust government health agencies.
1. Strongly disagree
2. Somewhat disagree
3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

36. Government health agency have my best interest at the forefront.
1. Strongly disagree
2. Somewhat disagree

3. Neither disagree nor agree
4. Somewhat agree
5. Strongly agree

37. The government has been very transparent with COVID details.
    1. Strongly disagree
    2. Somewhat disagree
    3. Neither disagree nor agree
    4. Somewhat agree
    5. Strongly agree

The following question is an optional, anonymous question. Please answer in 1-3 sentences.

38. In your opinion, what can be done to strengthen people's trust in the healthcare system?

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