

Racism and Trust in American Healthcare and Biomedical Research

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On my honor as a University Student, I have neither given nor received
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Introduction

Black Americans have endured racial discrimination for centuries in the United States. Although a grave reality, not much attention was paid to their adversity until the murder of Trayvon Martin in 2013 (Krieger, 2020). This sparked the development of the Black Lives Matter movement, at which time outraged Black Americans in addition to people all over the world began protesting against police brutality. In 2020 the Coronavirus (COVID-19) pandemic ran rampant all around the world, tensions were heightened in all communities, and people all alike were wondering what the state of themselves, and their families would be. On May 25, 2020, the murder of George Floyd and the subsequent video of the tragedy escalated tensions even further (Krieger, 2020). Black people were tired of being treated unfairly and dying at disproportionate rates. In addition, the COVID-19 pandemic was also claiming Black lives at disproportional rates. These two issues together exposed the racial attitudes of many individuals and groups towards each other and additionally revealed the attitudes of Black Americans specifically towards the American healthcare and biomedical research system. As people worldwide eagerly awaited the development of a COVID-19 vaccine, Black Americans were both afraid and conflicted about whether to trust the vaccine if available. This was due to the numerous occurrences in which the American healthcare and biomedical research system demonstrated that Black lives were not important to them. Why were Black people who are dying 50 to 80% more than other racial groups due to this pandemic, refusing to accept the COVID-19 vaccine or as some called, the magic bullet (Moore, 2020)?

To fully understand the mistrust of the Black American ethnic group in contemporary medical systems, we need to take a step back to recognize the role of racism in American healthcare. After understanding this, we may be able to identify the cause of the mistrust, as it

may be due to various factors. The mistrust in the healthcare and biomedical research system may be due to general suspicion of the technology and science of therapeutics such as vaccines. It might also be due to the power and politics behind the therapeutics, or perhaps, any combination of historical, institutional, or clinical factors. In this thesis, I will use a historical perspective to examine the continuous history of racism in the American health system and its entanglement with science and technology. What institutional or political factors determine the inclusion or exclusion of Black Americans in biomedical studies? How does the current practice of healthcare affect the trust of Black Americans in healthcare systems? I will be utilizing COVID-19 as a case study to further address this issue.

Literature review

The current economic status of most Black Americans is not representative of their hard work or efforts in life as the system in which they live, makes it extremely difficult to succeed. The current economic status of most Black Americans is a direct consequence of the oppression, injustice, and lack of opportunity they have endured since the beginning of slavery in the 1500s (Ponti, 2019). Black Americans have still not “recovered” from the effects of their grueling past, the systems put in place by the government are not assisting them in their efforts to heal and recover. Instead, we see that Black Americans make up 39% of inmates in prisons, although they constitute only 13% of the population (“Inmate Race”, 2021). We see that Black Americans represent the largest sector of individuals in poverty in the United States (Nan, 2019). We see that Black women and their children have the highest mortality rates in the nation due to preventable measures in childbirth. Accordingly, the poor socio-economic status of Black Americans is not by their own doing (PovertyUSA, 2020).

In times of slavery in the United States, medical doctors would articulate lies, claiming that a clear anatomical distinction between Black people and White people existed, giving reason to believe that skin color could dictate superiority (Byrd, 2001). Over time, as the United States slowly transitioned out of slavery, false proclamations such as these dissipated, however with it, new and incorrect stereotypes were developed. To this day there are doctors and nurses in the United States who genuinely believe that Black people feel pain differently and/or have tougher skin than White people. As a result, Black people who are treated by doctors with these incorrect stereotypes, are not provided with the level of care and compassion in healthcare settings as compared to their White counterparts which further perpetuates the issue of trust.

When we ask ourselves what roles the stereotypes played in history, it can be seen that politically and economically, the United States' climate during slavery greatly benefited as a result of the racial stereotypes. The rationalization for slavery might have been needed to continue the growth and development of the United States' economic status at the expense of Black people. As a result, doctors, as trusted individuals in the community, played their roles in the racist and unjust system by bolstering false information. Although the era of traditional slavery in the United States ended, it is clear that in the healthcare and biomedical systems, racism still continues. A report by the Institute of Medicine in 2002 stated that "minorities were less likely to be given appropriate cardiac medications ... undergo bypass surgery... receive kidney dialysis or transplants, compared with their White counterparts (Thomas, 2019). So, what role does racism *currently* play in the healthcare and biomedical research system, and how does it affect trust? By investigating this question, we will get closer to understanding racism and trust in the American healthcare and biomedical research systems.

In the United States, Black Americans are the least likely racial group to attend a four-year university. Correspondingly, the understanding of complex contemporary medical issues is not simple. When thinking about contemporary healthcare in the United States through the lens of Black Americans, the dissonance is immensely present. Questions such as: should I trust what the doctors and researchers say is good for me, or should I learn from the countless examples in recent history that show that these contemporary medical systems are untrustworthy, arise. Furthermore, the announcement that the approval and subsequent dispersion of the COVID-19 vaccine would be processed through the FDA's *Emergency Use Authorization* (EUA) was not satisfactory in the hearts of Black Americans and further perpetuated the dissonance.

In history, the lack of sufficient investigations of pharmaceuticals has led to detrimental effects. Thalidomide, a pharmaceutical developed in the late 1950s was a sedative used to treat nausea in pregnant women. After the distribution of the drug in countries worldwide, approximately 10,000 children were born with deformations including phocomelia, limb malformations, ventricular septal defects, autism, and Duane syndrome due to the lack of thorough research on the drug (Kim, 2011). Although the development of Thalidomide was not race-related, its failures demonstrated that small errors by medical researchers and blatant trust in therapeutics given by doctors could result in detrimental effects. The lesson learned in this case could be representative of the current EUA of the COVID-19 vaccine. This example could be a possible partial explanation for the mistrust of Black Americans (not exclusively) in healthcare and biomedical research systems. Furthermore, the general public is not knowledgeable enough concerning the complexities of drug development. As a result, much faith is placed in others (doctors and healthcare personnel) to have their best interests at heart. The lack of background knowledge required to thoroughly understand the explanation and probability for complications

in a pharmaceutical like Thalidomide can promote fear and uncertainty for most people. How are people sure that history is not repeating itself? Especially for Black Americans who have been shown that they are not cared about, how do they ensure that history *will not* repeat itself? This is a question of trust.

We can now transition to examples of the healthcare and biomedical research systems failing the Black community in its investigations. From 1932 to 1972 a public health service study named the Tuskegee Syphilis Study was conducted. The study was exposed as a nationwide scandal, and its effects are still being reverberated in the Black American community today. The study involved the conscious and deliberate injection of syphilis into 399 unsuspecting African American males who were told that they were being cured of their “bad blood”. The actual purpose, however, was to study the effects of untreated syphilis in Black people. The African American males after being infected with syphilis were not told about or provided with the antidote for the disease although available. Instead, they returned to their communities, unaware of the disease they had been infected with, and spread syphilis in the African American community (Green, 2011). This painful reality, unforgotten by many Black Americans, is yet another reason why trust is lacking between their community in the healthcare and biomedical research system.

This is seen again in the case of an African American woman, Henrietta Lacks who in the 1950s was stripped of her cervical cancer cells that were subsequently distributed worldwide without her knowledge or consent. Her cells which were instrumental in the development of many scientific breakthroughs are nevertheless used today. They are currently the most common cell line to be cultured in scientific laboratories. The family of Henrietta Lacks neither gained knowledge nor compensation for the contributions she made to the scientific community,

although countless institutions currently profit from her cells (Khan, 2011). Of course, informed consent is now standard of practice in the United States healthcare and biomedical research system, so it is improbable that an individuals' biological information may be taken and distributed without their consent, however, racial iniquity, as shown in this example, is still very much a possibility.

When we ask the question, what can be achieved to sever the barrier of mistrust between Black people and the medical community, we must first reflect on whether matters have improved from the past, or if history is repeating itself (except now more implicitly). Currently, the distribution of funding towards research efforts for diseases that mainly affect Black people is severely less than the funding given to diseases that commonly affect White people. Sickle cell anemia/disease which predominantly affects Black individuals is 3 times more common in the population than cystic fibrosis which predominantly affects White people (Power-Hays, 2020). In 2020 alone, cystic fibrosis received 7 to 11 times the research funding (per patient) than sickle cell did (Power-Hays, 2020). So, are matters getting better?

The literature overall has shown that the American healthcare system is still highly racially biased. So, was race built into the American healthcare and biomedical research system before, during, or after the construction of the system? To understand the entangled relationship between racism and American contemporary medical systems, we need to examine whether these factors (economical, medical practice, knowledge) are still race dominating and if they are playing a role in the attitudes of individuals and communities towards COVID-19.

Ethical Framework

In general, the response to the question, what can be done to sever the barrier of mistrust between Black Americans and the medical community, is the acknowledgment, admittance, and

subsequent apology by both the government and the medical community for the atrocities that have been committed at the expense of Black people. However, the question following question in response is, *who specifically* will apologize, and will the apology fix the mistrust?

“Can one do evil without being evil?”, this question forms the basis of the Banality of Evil (White, 2020), a theory asked by Hannah Arendt in 1961. She wrote an article concerning a Jewish man in Germany whose job was to schedule transport for Jews to be taken to concentration camps during the holocaust (White, 2020). Although an extreme and unfortunate event, it serves as a good example of the complexities that discriminatory systems have. Referring back to the original question asked, *who specifically* will take the responsibility for the atrocities that have befallen Black Americans in the healthcare and biomedical research system, there is no correct answer due to the intricacies and division of responsibility in the system. The mechanism by which the American healthcare and biomedical research system were designed innately contains various factors that it racist. No one person is responsible for everything, as a result, microaggressions, and even inadvertent aggressions occur that can add to one individuals’ experience regarding racism. When we ask the question, how do we sever the mistrust or rather build the trust of Black Americans in the contemporary medical system, the reality is, it cannot be done without redesigning the entire system.

Let us take the example of Eunice Rivers, an African American nurse who served as a bridge between the Black community and the medical researchers during the Tuskegee Syphilis Study. Many historians debate whether she was merely doing her job and did not care about the lives of her fellow Black man, or, whether she was doing what she had to stay employed, in addition to other reasons. The situation was however not as black and white as it now sounds, just as racism in the healthcare system is not black and white.

Historians have argued that Eunice Rivers accepted the job offer due to many factors including that: the country was going through a depression and as a result, job opportunities were scarce (Kearns, 2013). Additionally, as a woman of color at that time gaining employment was extremely difficult, so she had to take the job. They also argue that she thought because a corresponding study which investigated the effects of untreated syphilis in White males was also being conducted, that what she was doing was not wrong nor racially motivated (Kearns, 2013). However, what all of these explanations do, is demonstrate the complexity of racism in the healthcare system. If Eunice Rivers did not accept the job offer, would another African American woman likely fill her place? When we contemplate this question, it is even easier to recognize that racism is innately built into the healthcare and biomedical research system. This example was to show that sometimes, racism or injustice to the Black American community, does not only come “directly” from the White man.

A recent article on the Banality of Evil as related to the COVID-19 pandemic explained that, at this time (years of 2020 & 2021), we have a unique opportunity to rebuild the healthcare and biomedical research system from scratch (Leonardi, 2020). This means that individuals from all backgrounds would be able to have sufficient access to healthcare and health insurance (Leonardi, 2020). The article suggested that for this to happen, multiple relevant social groups (politicians, clinicians, policymakers) would have to come together to rebuild the system however, if none of them decide to take partial responsibility for the general failure of the healthcare system, then nothing would be achieved. Ethically, given the opportunity to rebuild something that has disadvantaged groups since its induction, are relevant social groups who have the power to change the system not obligated to do so?

Social Construct of Technology Framework & Research Method

In this investigation, the social construction of technology (SCOT) framework will be used to examine the interplay and interpersonal flexibility between race, drug/therapeutics, the healthcare system, and the biomedical research system. The SCOT framework views technology as a social construct and examines the diverse perspectives of the relevant social groups (RSG) which span from the inventors of technology to the users. To this end, the technologies investigated are the history, developments, and yields of the biomedical research and healthcare system. Subsequently, the RSG's are defined as the inventors of the technology and include healthcare personnel, biomedical researchers, and policymakers. The users of the technology are then the Black American community. With this framework, the investigation of the interplay and interdependence of these social groups with the associated technology will give rise to explanations concerning the mistrust of Black Americans in contemporary medical systems. The ultimate goal of this investigation is to identify potential areas of improvement for both the technology and the relevant social groups to allow the development of trust.

This research addresses sensitive topics in the current state of the world. As such, an objective perspective needs to be taken to achieve the best results. Surveys were conducted in the cities of Phoenix Arizona, Charlottesville Virginia, and surrounding areas. The surveys elucidate information on the attitudes of diverse individuals towards the American healthcare and biomedical research systems. It was expected that some responses would be from biased origins as the investigation deals with topics of race. Finally, as an individual who identifies as being part of the Black community, efforts to collect and analyze data objectively were made.

Data Collection

Several examples were given regarding factors in the past that have contributed to the mistrust of the medical system by Black Americans. We will now be centering on mistrust on an

individualistic level. As a community, Black Americans have countless stories and perspectives on the experiences they have encountered that have shaped their opinion of the American healthcare and biomedical research system. On the other hand, individual narratives provide a more personal and “raw” perspective when trying to understand the topic at hand. As a result, questions geared towards factors that result in the reluctance of the Black American community as a relevant social group to trust the vaccine, and questions geared towards the experiences from current methods of practice in healthcare as a technology were investigated through a survey. The responses from the survey shed light on race and discrimination in the healthcare and biomedical research system in current times. Surveys were conducted in both the Charlottesville and Phoenix community and were additionally available to individuals in surrounding areas. These two locations were specifically chosen due to the disparate ethnic demographics.

In Phoenix Arizona, the demographics were thus: 42.3% White, 34.7% Hispanic, 6.83% Black or African American, and 3.34% Asian (Data USA, 2020). In Charlottesville, 70.7% White, 5.8% Hispanic, 18.4% Black or African American, and 7.2% Asian (U.S Census, 2021). As a result of these varying demographics, the SCOT framework compared the experiences and perspectives from the participants (RSG) in these two cities to ascertain whether there were any differences in the attitudes (mistrust) toward the contemporary medical system (technology).

In total, 51 individuals from multiple backgrounds participated in the survey and the findings were collected and interpreted. The survey consisted of 24 questions. No willing individuals were refused from participation, and all questions were optional based on each

participant’s comfort level. The respondents from the survey were all between the ages of 20 and 30 years old although there were no age restrictions.

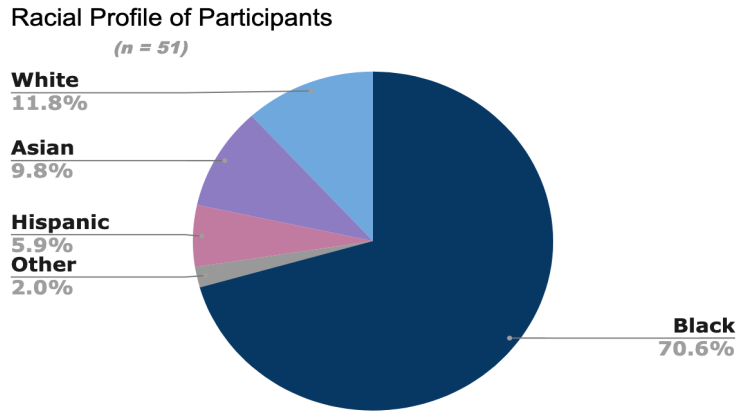


Fig.1 Racial Profile of All Survey Participants

Figure 1 reveals the racial profile of the participants involved in the survey. Backgrounds included: Africans,

African Americans, Hispanics, Asians, Caucasians, Pacific Islanders, and Mixed-Race individuals. For the sake of this investigation, Africans and African Americans were united into the Black category as the experiences of racism and discrimination based on an individual’s phenotype do not differ drastically between these groups. Interestingly, the results when separating by racial profile showed many similarities

Question	Response	
Do you trust the American healthcare system to take care of you?	Yes (15.7%)	Partially (66.7%) No (17.6%)
Are you aware of any misconceptions some healthcare personnel have about Black people?	Yes (76.5%)	No (23.5%)
Are you aware that Black people are dying at disproportional rates during this pandemic?	Yes (90.2%)	No (9.8%)
Are you aware that a majority of individuals in the Black community across the United States are reluctant to get the COVID-19 vaccine?	Yes (72.5%)	No (27.5%)
Have you gotten the COVID-19 vaccine?	Yes (88.2%)	No (11.8%)
Do you know anyone who has gotten COVID-19?	Yes (92.2%)	No (7.8%)
How likely are you to participate in a biomedical research study?	Likely (70.7%)	Unlikely (29.4%)
Do you think people are generally trusting of biomedical studies?	Yes (33.3%)	No (66.7%)

Fig.2 Selection of Questions from Survey with Corresponding answers from All Participants

within the groups however vast differences outside each group (excluding the Mixed-Race group

due to the small number of participants). In Figure 2, a selection of questions and responses from the deployed survey can be found. The chart displays a selection of questions of multiple-choice questions asked. Finally, participants were able to answer open-ended questions.

Results

The majority of respondents amongst all the racial groups when asked if they trust the American healthcare system to take care of them either answered partially (highest frequency of response) which was followed by the answer no. This could be due to several factors even before raising the issue of implicit racism or discrimination such as the availability of healthcare. For individuals who have access to free healthcare or have health insurance, the American healthcare system to an extent attempts to assist in their concerns and needs. However, for the majority of Black Americans, who typically do not have health insurance or adequate access to healthcare as compared to other racial groups, more mistrust in the healthcare and biomedical research system is present.

When we introduce the issue of racism and discrimination within the actual healthcare system where multiple relevant social groups including Black patients, doctors, and nurses interact, the American healthcare system (as previously suggested) is more explicitly untrustworthy and unfavorable, “African American women across the income spectrum ... are dying from preventable pregnancy-related complications at three to four times the rate of non-Hispanic white women, ... the death rate for black infants is twice that of infants born to non-Hispanic white mothers” (Jamila Taylor, 2019). This baleful reality is additionally reflected in the responses from the participants in the survey. A Black male participant shared, “If I were to have a wife who was pregnant [,] I worry about the baby’s birth if not handled by an African or African American doctor just because I see disturbing parental and maternal mortality stats

sometimes.”. When asked if they were aware of misconceptions healthcare professionals have about Black people the majority of Black people said yes, while one-third of Caucasians from the survey responded no (Caucasians were the largest racial group to respond no). This was interesting as the same group almost unanimously responded that they were aware of Black people dying at disproportionate rates in this pandemic. Are these results reflective of the White racial group at large? If so, it may be interesting to investigate the perspectives on healthcare personnel as a RSG also in this racial group.

Participants in the survey were then asked if they had faced any race-related adversity and discrimination in the context of contemporary medical systems. Numerous Black participants shared stories of the things they have encountered. One participant said “I was having an asthma attack one day. My friend took me to the ER at UVA[(University of Virginia hospital)] and then treated me badly. Instead of giving me a room they put me in the hallway. While I watch them put white people with less urgent matters in rooms”. Another said “Doctors are ... rude, don’t listen or are very short with me. This has happened when I go to the OBGYN, the emergency room, hospitals, and doctors’ appointments”. Finally, one participant said, “I have had a brother and a close friend almost die from being dismissed and misdiagnosed.” Contrastingly, when asked the same question, the White ethnic group unanimously responded “no”.

The majority of the female participants in the survey (aged 20-30 years old) have entered their child-bearing stages, and with prospects such as these, it is not unusual to see why they would be distrustful of healthcare professionals if they are people of color. Three separate participants described a common stereotype (Black people do not feel pain as much as White people do) concerning racist healthcare professionals that they had personally experienced when

asked if they had faced any adversity in a healthcare facility due to their race or skin color. One participant said, “[my] pain level [was] not being heard or believed, [I was] accused of lying about [my] symptoms or pain”. In the course of the survey, the notion that Black people have either higher or different pain tolerance than White people were mentioned 40 separate times. Interestingly, one participant mentioned that “my mother made sure to pick the only doctor who was our same ethnicity and spoke our language so that they would best treat us”. Although an effective remedy to bypass racism in the system, for the majority of Black American people in the United States, the availability of adequate health care is difficult to obtain, let alone the possibility of choosing their doctor. It is even more difficult considering that Black doctors only comprise 4% of all active doctors and physicians in the United States as of 2020 (Lipi Roy, 2020). This example, however, shows the interplay between these RSG’s in efforts to achieve equality, or simply, adequate medical treatment.

Discussion

At this stage, many anecdotes of experiences and perspectives from the participants regarding racism and discrimination in the American healthcare system have been presented. In surveying individuals from both the Phoenix and Charlottesville areas, it was predicted that there would be differences in the responses provided. However, although the demographics of both populations differ, the responses from the ethnic groups from both communities seemed to be consistent. As a result, responses were not separated by geographic location. Participants, all who had experienced the American healthcare system, were asked as a RSG in this investigation about what they think needs to happen to increase the trust of the Black community in the healthcare and biomedical research system. Many varied opinions were given, each with its reasoning. Figure 3 displays the major themes from the recommendations given by the

participants. One of the most frequent recommendations (in order of increasing frequency) was to require cultural competence training for all healthcare professionals, (meaning that healthcare professionals learn how to treat patients of all types and include diverse patients in their teaching examples).

Another frequent recommendation (as previously mentioned) was for the healthcare system and the government to be transparent about the past transgressions against Black people, apologies for them, and finally, give examples of how they will make sure things will improve. The participants from the survey also frequently mentioned that increasing racial representation and diversity of healthcare professionals would reduce the mistrust of the Black community against the healthcare and biomedical research system. This

intuitively makes sense as people generally trust other people that look like them however, if we refer back to the example of Eunice Rivers, we see that it is more complex than having community advocates, or doctors that are from the same background.

One surprising theme that was found was simply for healthcare professionals to listen and trust their patients when they tell them what is wrong. Healthcare professionals taking the time to

Suggestions to increase trust of the Black community in the healthcare and biomedical research system
Invest in medical clinics for the community
Doctors taking the time to get to know their patients
Apology of past transgressions
Expand the biomedical research studies to include black communities
Initiate coordinations with trusted institutions like churches and schools
Provide reparation for people who have been wronged
Revamp healthcare system
Treat patients equally
Educate doctors on how to treat all patients Include diverse patients in textbooks
Increase healthcare accessibility
Doctors should trust patients
Doctors should listen to patients
Adequate health insurance
Have doctors from the community
Have community advocates to educate community
Educate the community about what goes on in vaccine development and biomedical research
Require cultural competence training for healthcare professionals
Increase diversity and representation of healthcare professionals
Transparency about past transgressions

Fig. 3 Participant Recommendations for Increasing Trust in the Contemporary Medical Systems

listen to their patients and getting to know them would foster a more trusting environment, it would lead to the increase and willingness of Black people to seek medical attention when necessary. Although this would not fix the overall issue, it might lessen the negative entanglement of the Black American community as a RSG with contemporary medical systems, in this case, the technology.

In terms of the biomedical research system, researchers could implement is being explicitly clear about the motivations and processes that occur in an investigation as in explaining beyond the medical terms used in the consent forms provided. Additionally, although done (in some studies), biomedical researchers could provide monetary compensation to the participants which would increase the willingness of Black individuals to participate in the study and increase trust in biomedical studies.

The results from the survey reflected the examples presented in the literature review. The recommendations, taken from the mouths of diverse individuals in multiple geographic areas serve as a template for things that could be implemented to change the severe mistrust of the Black community in the overall American healthcare system. However, the only true solution would be to rebuild the system all over again as we have seen.

In this investigation, we wanted to understand why the Black American ethnic group has mistrust in contemporary medical systems. We examined historical examples to investigate the American health system and its entanglement with science and technology. We used the SCOT framework to examine how the current practice of healthcare affects the trust of Black Americans. This allowed us to understand the complex factors that result in the reluctance of the American community to trust the COVID-19 vaccine. Currently, in the United States, the percentage of White people who have received at least one COVID-19 vaccine dose is 38%

which is 1.6 times higher than the rate for Black people (24%) (Rodgers, 2020). The recommendations listed are not exhaustive by any means however, with the implementation of the recommendations from this paper, the trust of Black Americans in the healthcare and biomedical research system may increase slightly and as a result, might increase the willingness of Black people to accept and receive the COVID-19 vaccine.

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