

Sex Differences in Human Aortic Smooth Muscle Cell Phenotypes

(Technical Paper)

Racism and Trust in American Healthcare and Biomedical Research

(STS Research Paper)

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Introduction

The year 2020 revealed the political and social attitudes of many Americans with the Black Lives Matter protests/counterprotests and the 2019 coronavirus (COVID-19) pandemic. The presence of these major events raised nationwide tensions in all communities and triggered issues of racism entangled with the COVID-19 vaccine. Aside from this, the desperate desire for the vaccine or “magic bullet” was seen in the hearts of many Americans, especially those who experienced the loss of a loved one due to the pandemic. Coincidentally, the African American ethnic group which had the highest rates of loss (50–80% more than other racial and ethnic groups), was the largest group to report their reluctance to a coronavirus vaccine if available (Moore, 2020). To fully understand why the African American ethnic group has mistrust in contemporary medical systems, we need to take a step back to recognize the role of racism in American healthcare. From there, can we begin to understand precisely where there the mistrust comes from such as whether the mistrust lays in the technology or science of the vaccine, or the power and politics behind the vaccine. 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, technology, politics, and institutional factors amongst others. I will be using the COVID-19 vaccine as an endpoint in my understanding of how the various elements each contribute to current practices that allow the mistrust to continue.

Research Question

In this thesis, I will be investigating the effect of racism in the United States healthcare and biomedical research system on the trust that the African American community has in said system. Supporting research questions will be incorporated to investigate the main research question sufficiently. The supporting questions will encompass African American mistrust

attributable to historical, political, institutional, scientific, technological, or clinical factors. The first supporting query states: given that COVID-19 is a life-or-death threat, what factors result in the reluctance of the American community to trust a lifesaving vaccine? The second supporting query states: what institutional and political factors determine the inclusion or exclusion of African Americans in biomedical studies? The third supporting query states: clinically, how does the current practice of healthcare affect the trust of African Americans? Following these queries, an investigation will be conducted to ascertain the changes that need to be made to increase the trust of the African American community regarding the vaccine and the reduction of ethnic discrimination in the healthcare and biomedical system.

The coronavirus vaccine will be deployed to the public in the coming months according to leading studies. This investigation is imperative when thinking about the “best” or socially just method to release the vaccine knowing that significant amounts of individuals in the African American community are reluctant to accept it. As a member of the Black American community, I cannot help but feel the resistance to the coronavirus vaccine in the community. My parents, one who is considered to be in the “elderly” age group and the other a health care worker are both at a high risk of severely being affected by the disease. To that end, these realities in both my family and my community drive my motivation to understand and improve the situation around the trust of the vaccine in the African American community.

Literature Review

The prevalence of ethnic discrimination has played a significant role in the reputation of the United States health system. Ethnic discrimination began as early as the 1500’s when the first slave ship from Africa disembarked to what is known today as the United States (Ponti, 2019). Doctors and medical scientists contributed to a system of injustice that was created by the

political and economic system present at that time and implemented by the people of that society. Their contributions included the notion that slaves were biologically dissimilar and intellectually inferior to their white counterparts (Byrd, 2001). The social and political atmosphere relied on the survival of the ethnic discrimination network and directly benefited from the productivity of slaves with the economic growth that soon ensued, “universal assumption of black inferiority at the social, religious, and scientific levels ... served to rationalize, legitimize, and intensify medical participation in the highly profitable colonial slave systems” (Byrd, 2001).

Throughout time, racism in the healthcare system did not dissipate. It might have been assumed by many that the abolition of slavery in the United States which eliminated the social and political benefactors of slavery, would decrease racism in the healthcare system. However, the unjust conclusions made by the early doctors and medical scientists continued[s] to influence the minds of the public and negatively affected people of color. The gradual evolution of racism in healthcare continued to be rather slow. 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). Nineteen years later in 2020, some doctors still believe that black people have thicker skin and higher pain tolerance than their white counterparts. These incorrect beliefs explain the lack of trust which is associated with less doctor-patient interaction, reduced adherence to recommended treatments, poorer health, and reduced utilization of healthcare services” in the African American community (Nan, 2019).

The lack of trust was consistently fueled by discoveries such as the exploitation of Henrietta Lacks. In 1950, Henrietta Lacks, an African American woman, had her cervical cancer cells taken without consent. Her cells, known as immortal (HeLa) cells, are still used in

biomedical research today to conduct experiments, have contributed to countless scientific pursuits, and have accumulated multimillion-dollar profits in all its application (Khan, 2011). The family of Henrietta Lacks did not know of the exploitation of her cells until after 25 years after her death and did not obtain any of the profits gained by the numerous institutions (Khan, 2011). The discovery of the scandal reverberated in the African American community, increasing mistrust in the healthcare and biomedical research system. The Tuskegee Syphilis study is an infamous and “ethically unjustified” project that lasted from 1932 to 1972, organized by the Public Health Service and Tuskegee Institute. It involved both the conscious and deliberate injection of syphilis into 399 unsuspecting African American males who were additionally denied the cure for the disease (penicillin) when available (Green, 2011). These two cruel cases are examples of some of the injustices the African American community has faced historically, institutionally, and scientifically by the American healthcare and biomedical research system. It sheds some light on the blatant deceit the African American community has undergone at the expense of the health system.

With realities such as these, reluctance to participating in studies can be easier understood. A study showed that “psychological barriers to recruitment were perceived to be most prevalent in African American communities” and these barriers included the distrust of being tested on with unproven protocols or therapies and having negative effects, the misconception that they would be treated like guinea pigs, and generalized fear of the process (Tanner, 2015). This study partially explains the lack of diversity seen in biomedical research studies however, it does not explain the whole issue. Other factors contributed to the lack of representation in biomedical studies.

The Genome-wide Association Study (GWAS), based in the United States, was a large effort made to investigate the genetics of complex diseases such as coronary artery disease (CAD). Genomic data from over one million participants worldwide were involved in the study (Mills, 2019). However, the GWAS focused solely on European ancestry when the goal was to investigate complex diseases worldwide. As previously mentioned, in 2019, it was found that 96.27% of all GWAS participants were made of European ancestry while only 0.11% were African, 0.50 were Hispanic or Latin, and 0.00% were African American (Mills, 2020). When thinking about diseases such as CAD and diabetes, diseases most common in African American populations, how will the downstream results and products of the GWAS benefit these groups if their genomic data is negligible in the biomedical studies? Additionally, the nonexistent percentage of African American individuals in the study also hints that no efforts were made to achieve a diverse cohort in any fashion. The lack of representation of African American people is not solely due to their reluctance to participate, it heavily is due to the lack of prioritization of the healthcare and biomedical research systems to include them.

African Americans are the second poorest ethnic group in the United States (PovertyUSA, 2020). Access to food, education, and proper healthcare is significantly impacted and individuals who are most in need do not attain the help or support they need to survive. Sickle cell anemia is a disease that disproportionately affects Black Americans in the United States just like CAD. The presence of sickle cell in the United States is largely due to the slave trade that brought hundreds of thousands of people into the United States. Since that time, trends have shown that the healthcare system along with society continuously has not favored or supported the Black American community, especially regarding this disease.

Cystic Fibrosis is a disease that mainly affects Caucasians and has roughly 30,000 cases in the United States (Power-Hays, 2020). Sickle cell on the other hand which affects roughly 100,000 cases in the United States (Power-Hays, 2020). Despite that fact, cystic fibrosis receives 7 to 11 times the research funding per patient than sickle cell (Power-Hays, 2020). Currently, the Food and Drug Administration (FDA) has approved 4 medications for sickle cell and 15 medications for cystic fibrosis (Power-Hays, 2020). Because of the lack of attention that has been paid to African Americans in United States healthcare and biomedical research systems, African Americans find it difficult to trust the system due to recurring incidences of injustice as seen historically, clinically, scientifically, and technologically.

The lack of attention to African American communities can be seen politically as wealthier neighborhoods receive more state funding for clinics and long-term health care providers as compared to poorer neighborhoods. With better access to healthcare, better funding, and long-term health care providers available in the community, richer communities benefit from having the opportunity to create extensive/trusting relationships with their health care providers (Stanley, 2020). African American communities, on the other, do not afford this luxury due to financial instability (as previously mentioned, African Americans are one of the poorest ethnic groups in the United States).

How can improvements be made to reduce the factors that limit African American involvement in biomedical research and what changes can be made to increase the involvement and trust? How can improvements be made to increase political factors that can improve the quality of healthcare provided to African American communities? What overall changes need to be made to achieve the trust of the African American community in terms of the COVID-19

vaccine?

STS Framework

I will be utilizing the social construction of technology (SCOT) framework during the investigation of my research topic. 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 the technology to the users. The technology is seen as the medical system which includes the development, execution, and products of healthcare and biomedical research including the COVID-19 vaccine. The RGS's include the healthcare community including healthcare personnel (doctors, nurses, clinicians), the biomedical research community (scientists and recruiters), the political community (laws and policymakers), and most importantly, the African American community. The SCOT framework was chosen to examine and unfold the interplay and interpretational flexibility within race and drug /therapeutics, and the healthcare and biomedical research system. Investigating the interplay and interdependence of these social groups with the associated technical elements will shed light on the topic of African American trust in the "system". With this framework, I aim to discover the areas that can be improved to benefit the lives of those who are disproportionately affected by many factors stemming from race in the United States.

Methods for Data Collection

My research question focuses on sensitive topics in the current state of the world. As such, an objective perspective needs to be taken to achieve the best results. My data collection method will involve the utilization of prior data from supplemental research studies in addition to surveys. Thus, I will be obtaining information from historical papers, published journals, and studies that have provided insight into the topic already. I will additionally be deploying surveys

in the Phoenix and Charlottesville community with individuals from different ethnicities to understand the experience of diverse groups in health care or research settings and their opinions on the COVID-19 vaccine. I expect to have information from biased origins as my investigation deals with topics of race. Additionally, I aim to achieve an objective investigation by examining how the awareness of differences in ethnicity both benefit and impede the wellbeing of individuals. Finally, as an individual who identifies as part of the Black community, I aim to collect and analyze data from an unbiased point of view.

Timeline

I plan to have completed the STS portion of my final thesis by the beginning of March. By the end of the spring semester, I plan to have completed the literature research portion of my paper. I also aim to have prepared the interviews I plan to administer such that during January, I may have achieved the responses. My goal is to identify the gaps in the healthcare and biomedical research systems and subsequently provide possible solutions to narrow the gap.

Conclusion

This paper addressed the effect of racism in the United States healthcare and biomedical research system on the trust that the African American community has in said system. As an STS topic, this research directly looks at the intersection of social and technological development as it relates to healthcare and race. This topic is important especially in times like these when the world is pandemic-stricken and many members of an ethnic group in the United States have collectively decided to refuse a vaccine due to trust in the healthcare and associated system. Hopefully, these discoveries from this paper and other literature will be implemented to assuage the thoughts of many individuals in the African American community who genuinely believe the likelihood of being used as pieces experimentation for the vaccine, as seen many times

historically with negative effects, is greater than the scientific evidence which proves the efficacy of the vaccine. There is no doubt that the disproportionately rampant spread and mortality of COVID-19 within the African American community will be commensurate with their decreased economic status, resulting in a negative feedback loop.

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