Contextualizing COVID-19 Vaccine Hesitancy Among Black Americans

"*I do not want to be killed by a white doctor in America. I think I will be killed by a white doctor in America.*" – Kiese Laymon

Kiese Laymon, a Black author from Mississippi, describes his experience growing up in America, and the belief system that came with it.[1] "A white doctor has the power to kill you or save your life, and your best shot is avoiding health care at all costs."[2] Laymon advises other Black Americans: Should you have to visit a physician, dress as proper as you can, over-enunciate your English and hope and pray that it will be enough for them to look past your skin color.[3] The anxiety and mistrust reported by Laymon, and many other Black Americans, describes a phenomenon white Americans have been largely able to ignore until the rude awakening that is the COVID-19 pandemic. Health care is not an apolitical experience, and care systems do not cater to all in a universal way. The standard of care and the experience of receiving it are deeply contextualized.

Health care systems have been shaped and created by white medical providers and administrators for white patients. Historically, the standard of medical care designed for and offered to Black people has been substandard, grudgingly provided, and often resulted in extreme discomfort and mistreatment for many Black patients.

Not only have Black Americans been actively excluded from healthcare, but they have been historically viewed by this system as bodies for experimentation rather than patients or considered mere "anatomical material."[4] Educational institutions Virginia Medical College and the Georgia College of Medicine hired individuals until as late as 1919 to perform the role of "resurrectionist," entering graveyards to retrieve the bodies of newly buried Black people to be studied and dissected.[5] The 1920s marks the beginning of many compulsory sterilization laws for a variety of different minorities in the United States, which even after being repealed, continued

to be reported until the 1980s by many women without their consent.[6] As late as 2017, a Tennessee judge finally reversed a practice that allowed for inmates to shorten their sentence by thirty days should they subject themselves to sterilization, which would disproportionately affect Black inmates.[7] These infamous examples contribute to the structural violence that occurs in healthcare today, which is often overlooked by medical professionals.

The very foundation of Western biomedicine is built upon the exploitation of marginalized bodies, through unconsented experimentation. Advancements in the fields of oncology, immunology, and the polio vaccine are largely attributed to cells from a patient named Henrietta Lacks, who entered the Johns Hopkins Hospital in 1951 with cervical cancer. Without her knowledge or any kind of compensation, her cells were collected and used in many studies in practices which would be completely illegal today.[8] Commentary from the scientific journal *The Lancet* on Lacks' story also notes that she was born in the same cabin her enslaved ancestors lived in, showing that the freedom she supposedly had was not without loads of intergenerational trauma.[9] Although she herself may have been free, her identity as a Black woman placed her in the same patterns of structural violence and would eventually lead to the exploitation of her body as she lay on her deathbed.

The effects of this trauma are now more present than ever, when being a Black American increases the likelihood of being hospitalized after contracting the coronavirus 2.9 times and doubles the likelihood of death.[10]

The disproportionate distribution of illness associated with COVID infection in Black communities is compounded by a low vaccination rate which continues to trend all over the country. Both the disproportionate access to healthcare and the failure to understand the societal factors that create mistrust are linked to systems of institutional racism. It is only when these

historical trends are examined that the low vaccination rates in Black communities can be understood. It is a combination of a history of poor experiences with the medical system, and a lack of access as a result of health care systems that were never set up to serve them in the first place. It appears that many Black Americans are remaining unvaccinated because they feel it is the safer choice. Analyzing the discourse and ethnography of Black community leaders, and the social determinants of health that affect them, highlights how this is not a new phenomenon, and they have spent much of their lives fending for themselves. This paper will examine how the American healthcare system has continued to let down Black Americans for generations, culminating in the shocking disparity of health outcomes by race in the current COVID-19 pandemic.

When it is a matter of life or death, there is no time to wait for the government to come and support you. Across the southern United States, Black community leaders have been mobilizing whatever resources are at their disposal to combat the structural violence they are faced with. They are doing all they can to get their communities vaccinated.[11] In Louisiana, where 32 percent of the population is Black American and only 23 percent have been vaccinated, Cala Brown, a nurse in Baton Rouge, is working hard to get the word out that vaccination is essential in fighting COVID. “At your age, it’s the vaccine or the grave,” she states soberly as she reaches out to anyone she knows is feeling skeptical.[12] Although a passionate believer in vaccination, she must come to terms with the fact that many of her peers can recount histories of abuse at the hands of the American medical system.[13] She does her best to acknowledge this intergenerational trauma, as, for many, this mistrust in the system is the root of hesitancy in accessing vaccines. She believes that it is only by acknowledging the past that there is a chance of shaping a better future.[14]

Next door, in Tuskegee, Alabama, the infamous Syphilis study was conducted in 1932. Without their consent, six hundred Black men, many with syphilis, were studied and prevented from accessing treatment for the disease. The study took place in Macon County and was named the "Tuskegee Study of Untreated Syphilis in the Negro Male," though this was not publicized or even shared with the participants.[15] Societal norms leaning towards social Darwinism and an over emphasis on perceived differences between racial groups led to the development of this study as scientists hypothesized it would have different effects on Black and white individuals.[16] Black people were also thought to be more prone to sexually transmitted infections, an argument which was used to explain the low birth rates and high miscarriages amongst communities. This is false as it ignores many different impacts of structural violence that influence these issues.[17]

The study took place in Macon County due to its large population of Black sharecroppers. Out of those selected, 399 of the men had syphilis and 201 were without it to represent a control group. All were lied to and told they were participating in a study that would treat them for "bad blood," a colloquial term that referred to several different ailments.[18]

Praying on the levels of poverty in the community, researchers gave participants free rides to medical exams and meals during the study. They were also offered treatment for minor illnesses and "guarantees that provisions would be made after their deaths in terms of burial stipends paid to their survivors."[19] During the study men were given fake medication in order to continue to believe that they were being treated, and when penicillin became widely available to treat syphilis in 1947, they were all refused treatment. Lists with the names of the men in the study were even given to the Alabama Health Department to prevent them from seeking treatment anywhere in the state.[20] In 1972, when the discovery of what had happened in

Tuskegee was leaked to the public only 72 men remained alive, 128 had passed away from syphilis, 40 of the participants wives had been infected, and 19 children had inherited it.[21]

In 1997, the Clinton Administration issued an apology for the study, and the subsequent denial of treatment, with a promise to rebuild a nation where all feel safe utilizing medical systems.[22] One of the key statements reads as such: "We cannot be one America when a whole segment of our nation has no trust in America. An apology is the first step, and we take it with a commitment to rebuild that broken trust."[23]

Twenty-four years later, these claims appear to be no more than an empty promise. Men like Kiese Laymon continue to learn from experience that it is better to be sick at home than to leave the house and visit a doctor. This fear of harm at the hands of a medical practitioner is not to be confused with denial of science and should not be grouped as such. "It's not the science we distrust; it's the scientists."[24] So, what is it that these scientists are doing that makes people want to remain unvaccinated, despite the significantly higher risk that Black Americans face of both illness and death?

To understand this, one must turn to the social determinants impacting the health of Black populations in America, and how this has shaped their experiences of care. The imperial nature of the construction of the American nation, has left many to suffer at the hands of the state, due to multitudes of intergenerational socioeconomic barriers. Black Americans are infected by COVID-19 at much higher rates than their white counterparts.[25] On average, general health appears to be lower in Black American populations due to issues such as working lower paying front line jobs, living in neighborhoods without access to medical services, wealth and educational gaps, and overcrowded housing that prevents distancing from sick individuals.[26] All these are factors in the spread of disease during the current pandemic. This susceptibility to

illness is linked to structural barriers, not genetics.[27] However, recent efforts to provide preventative care to offset these factors have often been driven by an incorrect conflation of race and genetics. Such theories result in the belief that Black Americans are "marked for disease." This, in turn fuels further racism, leading to a medical perception that dark skin is inherently connected to being unable to take care of oneself as medical professionals start using it as an automatic risk factor for many different diseases, which in turn may lead to harmful internalization.[28]

Stereotypes play out in communities, and impact how individuals begin to see themselves. The harmful internalization of racist medical theories has led 80 percent of Black Americans to believe that the diet linked to their culture was the reason for their illness, as opposed to all the other factors that may contribute to an unhealthy lifestyle.[29] As a result, physicians have often attempted to "teach" patients how to live "better" lives, that will "tease" out traditional practices.[30] Despite promises to create further trust in these systems as stated in the Clinton apology, 79 percent of clinicians claimed a person's race would impact the treatment they gave them.[31]

On top of creating mistrust, misdiagnosis as a result of stereotyping has become common.[32] In one example, entering the hospital at the age of four, a young girl named Lela was diagnosed as "just another black girl with a fever and a cough."[33] Finally, four years later, a radiologist who had only seen her chest scan asked, "who's the kid with cystic fibrosis?"[34] The profiling and dismissal experienced by Lela could have cost her life. Rather than addressing structural violence that leads to individuals of a certain race to be more affected by an illness, many dominant medical systems places blame on the patient. Uncomfortable subject positions begin to form where a doctor is now an all-knowing power educating a Black person unable to

take care of themselves, and in Lela's case dismissing and invalidating a patient's concerns, perhaps even deeming them an overreaction. Reaching out for medical advice or care becomes difficult when it is met with these reactions. The role Black patients become forced into is not one that encourages further participation in medical settings.

The experience of belittlement and mistreatment from being automatically labeled as a vector for disease has led some to turn to community-based initiatives people feel they can trust. In 1970s Chicago, the Black Panthers started their own free health care clinics to allow members of their communities to access medicine and combat the structural inequalities that prevented Black communities from using mainstream sources.[35] The clinics they established in Chicago offered, for some, the first opportunity to access health care, allowing Black patients the chance to learn about medical practices, and providing a sense of agency. These clinics acknowledged the social and political factors that contributed to health and provided accessible spaces in a time where there were still accessibility barriers due to segregated hospitals in the Northern United States.[36] The clinic established by the Black Panthers was extremely robust and contained a variety of services, such as blood analysis, EKGs, gynecology, pediatric care, and psychiatric counseling.[37] These clinics were open seven days a week but faced constant scrutiny by Public Health officials for even the most minor violations. A1933 city ordinance declared that the Board of Health was allowed to request detailed personal information about individuals attending free clinics, and failure to meet this and other laws put in place would result in fines of $200 a day. When the leaders of these clinics refused to comply through the compromising of their patient's privacy they were shut down and replaced with city run subsidized neighborhood health centers. To replace these establishments clearly demonstrates that the city of Chicago was merely interested in taking away any agency marginalized groups could develop when seeking health

care. Their outcries for healthcare being a basic human right and something that is overly politicized lead to their downfall when it was made known to authorities. It is not hard to imagine that shutting down the only affordable and accessible way for some to seek care does little to create a sense of trust.

In 2021, as COVID-19 vaccine rollout takes place across the United States, community-based mobilization appears to be one approach that is contributing in a big way to what is getting shots in the arms of Black people in Louisiana. Vaccine clinics are located in predominantly white areas, providing a major logistical challenge for those lacking transportation, or working essential jobs that prevent them from taking time off work. This provides some insight as to why Black Americans are being vaccinated at half the rate of white Americans despite them being much more affected by the pandemic.[38] Ms. Brown has been working with the East Baton Rouge Council on Aging to provide vans for individuals attempting to seek vaccination but lacking transport.[39]As she goes door to door, she appeals to elders that have authority in the community reminding them of their role to encourage others to get vaccinated.[40]

There is often a disconnect between the reasons community workers cite for low vaccination uptake and the state-based strategies adopted to try and increase vaccination rates. Although the *New York Times* reports coming out of communities in Louisiana critique the location of clinics and need for cell phone or internet service to book an appointment, the Louisiana government has chosen a different approach to appeal to those who are not yet vaccinated. The "Shot at a Million" program is offering multiple lottery draws of up to one million dollars to American citizens not convicted of felonies who have received a shot.[41] The money to fund this has been taken from the Federal Coronavirus Relief Funds.[42] Once a winner has been selected for one of the draws, the money will first go back to the State of Louisiana to

recoup any debts owed.[43] This is not the only "innovative" attempt the state has used to try and increase vaccine uptake. The Governor took to popular social media app TikTok to boast about the state's "shot for shot" program letting eligible participants receive a free alcoholic beverage at participating bars once vaccinated.

These attempts to appeal to the unvaccinated population fail to recognize the multitude of structural factors that are keeping them from being vaccinated, and Black communities continue to have low vaccination rates. Those working directly with these communities see this as a result of structural violence enacted by the state. There is a disconnect when the solution their government has provided them is to invest millions into lotteries and drinking games that will be used to pay off debts putting money right back into the pockets of the state.

Many within Black communities do have trust in family doctors and community leaders, just not the state, which has a history of neglecting basic needs and failing to provide access to clinics.[44] State officials should be attempting to collaborate with Black Americans like Nurse Brown, to examine the exclusionary system that is holding back the state in vaccination numbers.[45] The programs set up in Louisiana that still neglects the needs of its Black citizens is yet another painful reminder of the failure of American Healthcare when it comes to adapting to serve diverse populations.

These struggles with vaccine accessibility are not unique to Louisiana. In Alabama, a state that does not even require vaccine providers to collect data on race, Black Americans are being forced to advocate for themselves. A community leader states, "we've got to fend for ourselves because no one else is going to help us. That's the way it's always been for poor Black people living in the country."[46] Just like in many other communities, the barriers regarding internet coverage and transportation make it difficult to secure appointments, but residents here

do not feel like they have a palace to turn to in order to seek help. It is almost an understanding that comes with being a poor Black person living in America. The system is not there to protect and look after you.

Although many Black citizens are working the frontlines keeping the country running, the system does not value them as such. On top of surviving in a global pandemic, they deal with the added pressure of taking time off work to advocate for their neighbors or register and drive them themselves. The state of Alabama has not made it easy to make do for anyone, as rejection of Medicaid expansion under the affordable care act and budget cuts leading to a 35 percent staffing reduction seem to be staking odds against people in the state.[47] With this state mandated destruction of resources and infrastructure there is very little wiggle room left for anyone that may struggle with accessibility issues or lacking the privilege to bypass them.

Where the state appears to be lacking in appealing to racial disparities of vaccine uptakes, some family doctors seem to have a better understanding of what is making people hesitant. The Cahaba Community health centers in central Alabama have produced several COVID-19 FAQ videos stating that the vaccine will be safe for any individual regardless of race and ethnicity, trying to ease skepticism, using whatever trust or influence they have to encourage people to get vaccinated. Hearing these words from a familiar face as opposed to governmental systems that present themselves with many unknowns shrouded in medical jargon, will hopefully provide the state with the results they need to see. This demonstrates the level of understanding that family doctors have, as they realize fears of medical racism are what are preventing their patients from seeking the vaccine, not the lack of a grand prize lottery.

Regardless of the effect this has however, family doctors cannot magically make vaccination sites occur in the neighborhoods that are being neglected, and they cannot provide

their patients with a home phone and internet access needed to book appointments, nor the vehicles to get them there. Though their work may be helpful, it is only when mass mobilization comes from officials that numbers will rise.

The so-called “trusting” relationships that the American government has claimed to rebuild with Black citizens has neglected the implications of the historical trauma they themselves have caused. Although they may attempt to move past it, the intergenerational wounds that have come from it are ever present in the face of the COIVD-19 pandemic, when survival depends on following the advice of people such as Dr. Anthony Faucci, Chief Medical Advisor to the President of the United States, under the assumption that they have your best interests in mind and will look out for you despite a past track record of doing the opposite. Black Americans—just as anyone else would—will not frequent establishments and institutions they believe will cause them more harm than good, especially while the vaccination rates remain so low in their own communities, stopping them from seeing any positive outcomes of the shot.

The utilization of preventative care to try to mitigate health risks among vulnerable communities has created even more structural racism in medical institutions, justified as genetic trends. This neglects the situations members of different races have been forced into because of discrimination. The harmful narrative it produces, by constantly painting Black Americans as lesser, removes the blame from the institutions that should be working to remedy the issues like lack of access to basic health care clinics. The American government, and individual state governments need to start listening to and uplifting Black voices. These communities know what they need and what is stopping them from getting vaccinated. Leaders like Cala Brown in Baton Rouge, Louisiana are doing phenomenal work that should be supported and backed by the state. However, most importantly, this work should not have been left to her. It is the responsibility of

a government to take care of its people, not provide them with gimmick lotteries to push vaccination. This applies to all marginalized groups that have suffered at the hands of supposedly neutral medical systems. Years of ignorance and silencing have created a toxic cycle that has finally been starkly illuminated to white Americans by the COVID-19 pandemic. To rebuild the trust that is constantly spoken of means to listen to and uplift stories while acknowledging trauma that shows our dominant systems to be in the wrong. With a restoration of agency and community action that allows for everyone to be equally valued and involved in health care experiences, we will being to see the true potential of what these systems can do for society, hopefully before the next global health crisis hits.

ENDNOTES

[1] Kiese Laymon is a professor of English and Creative Writing at the University of Mississippi. His work includes, *Long Division* (Simon & Schuster: 2013), *How to Slowly Kill Yourself and Others in America* (Simon & Schuster: 2013), and the award-winning *Heavy: An American Memoir* (Scribner: 2018).
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