THE UNIVERSITY OF CHICAGO

COVID-19 Vaccine Hesitancy and the Role of Medical Mistrust

By

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August 2022

A paper submitted in partial fulfillment of the requirements for the
Master of Arts degree in the
Master of Arts Program in the Social Sciences

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Acknowledgements

A deep and heartfelt thank you to my phenomenal thesis advisor - Dr.Tan. I am incredibly grateful to have you as a teacher, advisor, and mentor. I feel so blessed to have been able to be part of your lab and learn from you. As a Black woman in academia, imposter syndrome is one of the obstacles I face daily and the way that you supported me and guided me throughout the year is something I will never forget. You invested time and energy to make me a better student and researcher. Your patience, advice, intelligence, humor, and ability to see how you can best help your students are just a few of the many things that made this year transformative and one of the best experiences I've had. This year was full of learning (and a lot of laughter); thank you for those moments and for this incredible adventure!

A profound thank you goes to my preceptor, Dr. Gugwor who served as a confidante and guide as I navigated the MAPSS program. You created an environment where all your students could be their most authentic selves and you never missed a moment to validate every one of us. Your support and encouragement in times where I doubted myself and my ability meant the world to me. While I learned technical skills from you, I also learned valuable life lessons. You welcomed alternative ways of thinking in your class and encouraged me to push back and challenge the concepts we learned in Perspectives. Given the topic of my thesis, I read a lot about structural racism and how living in a world as a Black person can leave you broken at times, but despite all that, you said "also remember how we make beauty in every land hostile to us for others to use".

Another set of thanks goes to my wonderful parents, my siblings, family, and friends who encouraged me to enter this program and supported me from day one. There is truly no way I would have graduated without you all. I love you all deeply and dearly!

I would also like to recognize Dr. Tracy Gleason who was my professor and thesis advisor at Wellesley College. You imbued me with the necessary skills and knowledge so that I could complete a Masters thesis. Our relationship is one I value, and I am forever grateful for the foundation you gave me and your continued encouragement and support. Thank you!

Abstract

Vaccine hesitancy is important to examine to understand disparities in vaccine uptake and improve public health in the United States. Despite accessible vaccines for COVID-19, Black adults in the U.S. have some of the lowest vaccination rates compared to their White counterparts, and medical mistrust may be a critical factor that drives this hesitancy within the Black population. The purpose of this study was to investigate the association between medical mistrust and hesitancy in receiving the COVID-19 vaccine, as well as examine whether identifying with the Black/African American culture correlated with medical mistrust and vaccine hesitancy. A survey was developed to understand factors associated with vaccine hesitancy within the Black community. The investigator-initiated 38-item survey assessed beliefs and behaviors regarding COVID-19, the COVID-19 vaccine, and attitudes toward the medical system; the survey also included the Interracial Attitudes subscale of the African American Acculturation Scale to assess identification with traditional African American culture. Adults (aged 18+) who self-identified as Black/African American (N=53) were recruited from the community (local health fair, college campus, etc.) in two major U.S. cities and completed the survey on paper. The majority of participants (54.9% U.S. born, 45.1% immigrants) reported receiving the vaccine (86.8%), yet half (50%) endorsed hesitancy to receiving it. Additionally, 26.4% reported that they did not trust the medical system to keep them healthy, and 39.5% expressed a general mistrust towards the government. Compared to those who were not vaccine hesitant, respondents who were vaccine hesitant reported lower rates of trust in the medical care system ($M = 2.77$, $SD = 1.18$; $t=4.15$, $p < 0.001$). We also found that respondents who were vaccine hesitant reported higher rates of distrust in their healthcare providers ($M = 2.42$, $SD = 1.02$; $t = -3.11$, $p < 0.05$). There was no significant difference between those with hesitancy versus

without in identification with traditional African American culture nor was identification with African American culture correlated with medical mistrust in this sample. In this sample, many Black adults received the vaccine; however, about half reported hesitation to do so, and distrust in the healthcare system was associated with this hesitancy. Future research with larger samples should explore mistrust towards the U.S. government to better understand hesitancy in the Black community.

Introduction

In 2020, the world was irrevocably changed with the presence of a new zoonotic disease: SARS-CoV-2, colloquially known as COVID-19. COVID-19 has claimed the lives of millions of people worldwide and has earned the title of the deadliest pandemic in United States history (CDC, 2020). According to the CDC, as of June 14, 2022, there have been over 85 million reported cases and over one million deaths from the COVID-19 (CDC, 2020). While people worldwide have felt the widespread negative impacts of COVID-19, the virus made salient the astounding and persistent structural racism embedded within the United States. Black Americans are disproportionately affected by COVID-19; African Americans/Black Americans are more likely to contract COVID-19 and over three times more likely to die from it than their White counterparts (Laurencin, 2021; Siegel et al., 2021). Therefore, when the COVID-19 vaccines (Moderna, Pfizer, and Johnson & Johnson) were made available to the public, many states attempted to prioritize and vaccinate these vulnerable and high-risk populations (Persad et al., 2021). However, despite these efforts, when compared to other racial groups, the Black communities' vaccination uptake rates were lower (Bogart et al., 2020).

It is important to have a holistic view of the driving forces behind Black/African Americans' lower vaccination rates. Some factors are structural such as inhibited access to vaccination sites (McFadden et al., 2021), while others are socio-cultural such as the circulation of misinformation (Laurencin, 2021), concern about potential side effects of the vaccine (Razai et al., 2021), and overall vaccine hesitancy (Padamsee et al., 2022). Research shows that Black/African Americans are more likely to express hesitancy regarding COVID-19 vaccination compared to the White population (Moore et al., 2021). In fact, after the release of the COVID-19 vaccines, social media and multiple news outlets reported on the increased skepticism and hesitancy within ethnic and racial minorities (Muñana 2020). The determinant of interest and one that should not be overlooked in the decision-making process of vaccine uptake is medical mistrust (a lack of trust/skepticism in medical institutions) which is more apparent in the Black/ African American community (Bogart et al., 2020). Most Black/African Americans are aware of the various ways in which society is racially prejudiced and how people and institutions perpetuate that discrimination. While studies have examined socio-demographic correlates of vaccine hesitancy such as gender, socioeconomic status, education level, residency, and age, few have looked at whether identification with Black/African American culture is a predictor in vaccine hesitancy (Savoia et al., 2021). Therefore, in addition to studying medical mistrust as a determinant in vaccine hesitancy, the current study aimed to investigate whether identifying with Black/ African American culture was associated with vaccine hesitancy. Given the historical and contemporary experiences of racial discrimination it is important to explore the extent to which both medical mistrust and identification with traditional African American culture influence vaccine hesitancy.

Health Belief Model (HBM)

Despite the availability of the COVID-19 vaccine, many Black Americans are hesitant (Willis et al., 2021). To understand this hesitancy and how it applies to vaccine uptake, the Health Belief Model (HBM) provides a helpful framework. When it comes to the individual decision of choosing whether to get vaccinated or not, one must look at both the benefits and the consequences of the decision. The Health Belief Model (HBM), developed by Rosenstock (1966) posits that health behavior(s) center on the individual's perception on the severity, susceptibility, and benefits/risks of the health behavior in question (in this case, vaccination) (Al-Sabbagh et al., 2021). The HBM encompasses six constructs that affect health behaviors. Such constructs are: "perceived susceptibility, perceived severity, perceived benefits, perceived barriers, motivation and external cues to action" (Al-Sabbagh et al., 2021, para 3). Vaccination uptake is the result of an individuals' belief(s) on how susceptible they are to contracting COVID-19, how severe the impact of COVID-19 would be if infected, the benefits of the vaccine, and the perceived risks of getting vaccinated (Berg & Lin, 2021). In Cheney and John's (2013) work, they found that the HBM constructs were significant when predicting influenza vaccine uptake.

The same constructs can be applied to the COVID-19 vaccine. Peoples' decisions to either get vaccinated or stay unvaccinated stems from how they view the severity of COVID-19 (perceived susceptibility) and their understanding of any negative consequences associated with vaccination/not getting vaccinated (perceived severity). Researchers found that vaccination uptake was higher when individuals saw influenza as an imminent threat and were therefore 5.4 times more likely to be vaccinated (Cheney & John, 2013). They also found that medical mistrust was not a significant predictor of influenza vaccination (Cheney & John, 2013). While both COVID-19 and influenza are vaccine preventable diseases (VPD), COVID-19 is unique in the way that its genesis was highly politicized and therefore polarizing (Bolsen & Palm, 2021).

From the moment COVID-19 forced the U.S. into a national state of emergency, there were a variety of conflicting reports from conservative and liberal media outlets about the severity of COVID-19, its risk to people, and preventative measures to be taken (Bolsen & Palm, 2021). The intense circulation of misinformation overall fueled general mistrust and skepticism pertaining to COVID-19 (Priniski & Holyoak, 2022). Trust is an important component in how individuals receive and incorporate the information given to them. Individuals who are vaccine hesitant may believe that while COVID-19 serves as a formidable threat, the cost of vaccination which means engaging with the healthcare system, is more severe. This is when the perceived barriers component of HBM becomes important - "an individual's belief about the physical and psychological costs of getting vaccinated" (Cheney & John, 2013, p.2). Such beliefs vary from person to person and for many people, there is fear, anxiety and mistrust associated with the COVID-19 vaccine. However, the individual's "risk assessment can be influenced by a variety of factors including cues to action from trusted sources of information, and the social context in which they live and interact" (Badr et al., 2021). Studies show that when health care professionals endorse vaccination, vaccination rates typically increase (Cheney & John, 2013). However, if individuals do not trust sources of information, then they will not be moved to action.

Medical Mistrust

From the moment Black people forcefully arrived in the United States in chains, their relationship to the world of medicine was characterized by brutality, gross mistreatment, and horror. For the purposes of this study, we will define medical mistrust as the "distrust of healthcare providers, the health care system, medical treatments, and the government as a steward of public health" (Bogart et al., 2020, p.200) and as "absence of trust that health care

providers and organizations genuinely care for patients' interests, are honest, practice confidentiality, and have the competence to produce the best possible results" (Hostetter & Klein, 2021, para. 4). A history of unethical research and experimentation in the African American/Black population furthers hesitancy to engage with the healthcare system, thus paving the way for medical mistrust (Williamson et al., 2019). Black Americans' trust and faith in the healthcare system have been shaped through years of systemic racism and contemporary acts of discrimination actualized in the healthcare field (Privor-Dumm & King, 2020; Pellowski et al., 2017). The centuries of medical exploitation and trauma have generated a real and justified mistrust towards the healthcare system.

During the antebellum period, many physicians preferred to use Black people for experiments because they believed that Black people could endure more pain than White people (Trawalter & Hoffman, 2015). Since the common discourse during slavery was that Black/African Americans were impervious to pain (a belief that was substantiated and corroborated by medical professionals at the time), they were treated with more brute force and violence (Trawalter & Hoffman, 2015). Their proclaimed immunity to pain is what not only fueled the justification of slavery, but what posited Black men and women to bear the brunt of medical abuse, to be used as sources of evidence for white ideas (Trawalter & Hoffman, 2015). This belief, in addition to the fact that enslaved people were viewed as property and therefore did not need to give consent to these procedures, led to many White doctors conducting experiments on enslaved persons (Washington, 2010). Between 1845 to 1849, Dr. James Marion Sims (known as the father of gynecology) used enslaved African women to develop a procedure to cure vesicovaginal fistula (Wall, 2006). Even though Dr. Sims' work led to the successful treatment of vesicovaginal fistula, his pathway to success was actualized by exploiting Black

women's' bodies. Enslaved women were not granted bodily autonomy and the lack of respect for Black persons' personhood and dignity were codified into U.S. institutions over time.

More recent injustices, such as the infamous Tuskegee experiment further contributes to and solidifies Black individuals' feelings of mistrust (Jaiswal, & Halkitis, 2019). The Tuskegee Syphilis Study was conducted from 1932 to 1972 in Tuskegee, Alabama where hundreds of African American men were recruited and told they were being treated for bad blood (Corbie-Smith, 1999). The participants who had contracted syphilis were not given the proper course of treatment so that the effects of syphilis could be studied. In his book, *Bad Blood: The Tuskegee Syphilis Experiment — A Tragedy of Race and Medicine,* James Jones wrote "No scientific experiment inflicted more damage on the collective psyche of black Americans than the Tuskegee Study" (Jones & Tuskegee Institute, 1993, p. 220). This breach of trust and its effect on the psyche of Black Americans is still seen today; researchers surveyed Black and White residents of Jefferson County, Alabama and found that participants who had knowledge of the Tuskegee Study were less likely to participate in federal research (Freimuth et al., 2001). Another recent example that demonstrates the medical field's blatant disregard for protecting people of color is the story of Henrietta Lacks. Henrietta Lacks was an African American woman who was diagnosed with cervical cancer at the age of 31. In 1951, she received treatment at John Hopkins University and some of her tissue was biopsied (Klitzman, 2022). While most cancer cells eventually die after a few rounds of replication, Lacks' cells never stopped dividing - her cells were, for lack of a better word, eternal. Lacks' immortal cells (dubbed HeLa cells) are the reason behind many milestones in biomedical research and numerous medical advances like the polio vaccine (Masters, 2002). The case of Henrietta Lacks demonstrated how Black/African American people are consistently exploited for the sake of scientific discovery. Black/African

Americans have numerous concrete examples of the medical institution violating the four tenets of medical ethics - autonomy, non-maleficence, beneficence, and justice when it comes to people of color.

While we can see medical mistrust as a player in the COVID-19 epidemic, we can also see its manifestation in the HIV/AIDS pandemic in the 1980s. Gaston and researchers (2012) found that African American males' low adherence to treatment could be traced back to an overall mistrust of the healthcare system. An unfortunate reality of being a member of a racial minority also means an awareness of racism in various settings. Research has shown that medical mistrust, which is higher in racial minorities, translates to a series of outcomes associated with maladaptive health behaviors such as not following medical advice, disengagement with healthcare providers, and not taking advantage of preventative health measures like vaccination and screening (Bogart et al., 2021). When patients trust their medical providers, they are more likely to adhere to their treatment plan and follow the doctors' advice (Abel & Efird, 2013). Since marginalized groups such as Black/African Americans are more likely to experience discrimination in healthcare settings, Black patients are left in a unique space of uncertainty on whether to follow doctors' orders (Bleich et al., 2019). Aside from historical accounts of mistreatment, there are also numerous contemporary cases of mistreatment against Black people in the healthcare field. When a healthcare provider mistreats a Black person, trust is degraded between the two entities, and this impacts the treatment Black people receive. One study highlighted how medical students believe Black people can tolerate more pain than White people due to biological differences (Hoffman et al., 2016); this belief leads to differential treatment and therefore, a difference in health outcomes for Black/African Americans.

The prejudice that permeates healthcare fields has negative health outcomes which is evidenced in the black-white health gap in numerous diseases and health conditions (Bleich et al., 2019). For example, when comparing White and Black women's propensity to die from pregnancy complications, Black women are 3x more likely to die from pregnancy complications than White women (Centers for Disease Control and Prevention, 2021). Overall, Black people endure unique challenges in the medical field because of their race; such obstacles include not being believed by physicians, more aggressive forms of treatment, and lack of support by medical professionals (Taylor, 2020). The supposed obstetrical and gynecological hardiness of Black women is one of the many harmful stereotypes that leads to differential treatments and diagnoses for Black people, further fueling their mistrust of physicians. For communities of color, these past and recent experiences confirm the understandable need to distance oneself from the institution and its vessels that carry out medical abuse. Such cases show that medical mistrust is a result of years of systemic racism and could therefore be a powerful indicator of COVID-19 hesitancy amongst Black/African Americans in the United States. Medical mistrust is often viewed within a deficit lens because it is associated with poor treatment adherence, infrequent check-ups, and lower use of healthcare services such as preventive screening (Hammond, 2010; Williamson et al., 2019). However, while medical mistrust may seem to be wholly negative, research shows that medical mistrust can act as an adaptive coping mechanism. Medical mistrust protects individuals from engaging with a discriminatory institution by allowing them to maintain “meaning, control, and empowerment” (Bogart et al., 2020). Medical mistrust manifests from historical, vicarious, and personal experiences of discrimination. We must address the extent to which mistrust of the medical field is ingrained in the social

consciousness of African Americans as this can affect their decision-making process regarding COVID-19 vaccine.

Vaccine Hesitancy

Due to social determinants of health, which the WHO (2021) defines as "the conditions in which people are born, grow, work, live, and age…They are the non-medical factors that influence health outcomes", Black adults are more likely to contract and die from COVID-19, making them a vulnerable population and in a heightened need to protect themselves against COVID-19 (Smith et al., 2021). Black individuals comprise 13.4% of the US population, yet account for more than 24% of COVID-19 deaths (Bogart et al., 2020). Even though COVID-19 vaccine's efficacy has been proven, White people are over two times more likely to be vaccinated than Black people (Laurencin, 2021). Researchers Khubchandani and Macias found that 26.3% of the US adult population expressed COVID-19 vaccine hesitancy, but this percentage increased to 41.6% within the Black/African American community ("COVID-19 Vaccination Hesitancy in Hispanics and African-Americans: A Review and Recommendations for Practice," 2021). The racism that is intricately woven into the fabric of the medical field (encompassing medical care and medical research) is a contributing reason why Black/African Americans limit their engagement with the institution and are 1) less likely to be organ donors, 2) less likely to participate in medical research studies, and 3) more likely to experience vaccine hesitancy (Laurencin, 2021;Williamson et al., 2019).

Vaccine hesitancy is defined as the "delay in acceptance, reluctance, or refusal of vaccination despite the availability of vaccination services" (Soares et al., 2021, p.175) and can encompass a spectrum of behaviors ranging from absolute refusal to delayed acceptance of a

vaccine (Willis et al., 2021). Vaccine hesitancy is not a new phenomenon that emerged alongside COVID-19. People have expressed hesitancy towards the diphtheria, measles, mumps, and rubella vaccines to name a few. For example, hesitancy around the MMR vaccine arose out of fear that the vaccination led to the development of autism in young children (Poland & Spier, 2010). In another case, the hepatitis B vaccine was associated with the development of multiple sclerosis (François et al., 2005). When hesitancy about the influenza vaccine was examined, researchers found an inverse association, meaning that as vaccine hesitancy increased, influenza vaccination uptake decreased (Quinn et al., 2019). While individuals may be vaccine hesitant for some vaccines, this does not mean this behavior persists and translates for all vaccines. Vaccine hesitancy is not a fixed health behavior, but one that can be influenced and affected by both the external environment and individual characteristics (Bolsen & Palm, 2021). When the Moderna, Pfizer and Johnson & Johnson vaccines were made available, people had a myriad of resistant reactions to the news ranging from hesitancy to absolute rejection of the vaccines because of their own personal beliefs in addition to the rhetoric surrounding COVID-19 (Priniski & Holyoak, 2022).

There is a myriad of socio-demographic factors that can predict an individuals' propensity towards vaccine hesitancy. Such determinants include age, gender, race/ethnicity, income, zip code, and education level (Willis et al., 2021). Vaccine hesitancy was reported to be higher with younger age groups, Black Americans, people in a low socioeconomic status, and individuals who live in Republican states (Tram et al., 2021). Many respondents who were vaccine hesitant experienced hesitancy out of fear of the possible unknown long term side effects of the vaccine (King et al., 2021). Additionally, people who had high vaccine hesitancy were also found to have a general mistrust of the COVID-19 vaccines and/or the government (King et

al., 2021). Compared to other racial/ethnic minority groups, data shows that vaccine hesitancy is the highest within the Black community in the United States (Willis et al., 2021).

Ethnic Racial Identification and Acculturation

Medical mistrust is associated with knowledge of medical racism coupled with vicarious and personal lived experiences of discrimination in the health field (Bogart et al., 2020). Black/African Americans experience discrimination in the education institution, the criminal justice system, and in healthcare settings. Studies show that the more someone identifies with their Black identity, the more they will perceive/notice racism and therefore more likely to harbor medical mistrust (Bogart et al., 2020). According to researchers, African American acculturation encompasses widespread thoughts, behaviors, and actions because of the racial socialization process – Cokley and Helm (2007) state that part of that acculturation is "having a certain amount of cultural mistrust towards Whites because of their racial oppression of Blacks" (Cokley & Helm, 2007, p.143). The development of that general mistrust towards White individuals is a natural part of the acculturation process (Cokley & Helm, 2007). Ethnic racial identification (ERI) is the "importance of ethnicity/race to one's identity and the feelings one has towards their ethnic/racial group" (Yip, 2018, p.171). Essentially, ethnic racial identification is the accumulation of one's feelings, thoughts and attitudes related to membership in an ethnic/racial group (Yip, 2018). While the linear relationship between ERI and medical mistrust is not proven, the perceiving of discrimination is related to both medical mistrust and ERI. Yip (2018) found that the more discrimination an individual endures, the more they tend to identify

with their racial group. ERI and discrimination have a positive relationship as individuals with a high ERI perceive more discrimination than those with a low ERI (Stepanikova & Oates, 2022).

Current Study

Understanding the root causes of vaccine hesitancy within this specific population can help guide us towards effective public health solutions geared towards increasing vaccine uptake within the Black/African American community. The purpose of this study was to investigate the association between medical mistrust and hesitancy in receiving the COVID-19 vaccine, as well as examine whether identifying with the Black/African American culture correlated with medical mistrust and vaccine hesitancy. Therefore, the following two hypotheses were tested:

Hypothesis 1: Medical mistrust will predict vaccine hesitancy.

Hypothesis 2: High ethnic racial identification will predict vaccine hesitancy.

Method

Participants

Adults (aged 18+) who self-identified as Black/African American were recruited for the study. We analyzed data from 53 participants who completed the questionnaire on paper. Subjects were recruited from the community (i.e., local health fair, college campus, etc.) in two major U.S. cities. Participants were included in the study if they identified as Black/African American and were at least 18 years of age. Participants were excluded if they did not identify as Black/African American or were younger than 18 years old.

Procedure

Before collecting data, the Institutional Review Board at the University of Chicago reviewed and approved the study. After the IRB approval, we posted flyers around the University of Chicago about the study, its aims, and we attended local health fairs to recruit participants. Participants completed the 38-item survey that assessed beliefs and behaviors regarding COVID-19, the COVID-19 vaccine, and attitudes toward the medical system/the government. Participants also completed the Interracial Attitudes subscale of the African American Acculturation Scale (Klonoff & Landrine, 2000) as well as the 7-item Generalized Anxiety Disorder scale (*Generalized Anxiety Disorder 7-Item (GAD-7) - Mental Disorders Screening - National HIV Curriculum*, 2015). On the first page of the survey, all participants read an introductory page explaining the purpose of the questionnaire and gave informed consent where the participant agreed to the study by proceeding with this low-risk survey. All participants were compensated with a $10 gift card to Dunkin Donuts upon completion.

Measures

The investigator-initiated survey was 38-items that assessed beliefs and behaviors regarding COVID-19, the COVID-19 vaccine, and attitudes toward the medical system; the survey also included the Interracial Attitudes subscale of the African American Acculturation Scale to assess identification with traditional African American culture. Items that assessed medical mistrust and government were adapted from a study examining medical mistrust because of COVID-19: “When it comes to COVID-19, Black people cannot trust healthcare providers”, “When it comes to COVID-19, doctors have the best interests of patients in mind”, “The government is hiding information about COVID-19”, and “COVID-19 is manmade” (Bogart et

al., 2021). See Appendix A for the entire survey. Demographic information such as gender identity, education level, zip code, and nativity status were also collected.

COVID-19 Vaccine Hesitancy

To assess COVID-19 vaccine hesitancy, participants answered the question, "Were you hesitant to receive the vaccine?" A participant was labeled as vaccine hesitant if they responded "yes" to this question. Conversely, a participant was labeled as not vaccine hesitant if they responded "no" to the question.

Medical Mistrust

To assess medical mistrust, participants responded to 5 items on the questionnaire using a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree). We analyzed medical mistrust as a continuous variable. We assessed medical mistrust based on how individuals answered the 4 medical mistrust questions: "I trust the medical care system to keep me healthy" (item 8 on the survey), "When it comes to COVID-19, I cannot trust my healthcare providers" (item 9 on the survey), "When it comes to COVID-19, doctors have my best interests in mind (item 10 on the survey)", and "I rely on my doctor to tell me information about COVID-19" (item 17 on the survey). Participants who answered "agree" or "strongly agree" to question 9, and "strongly disagree" and "disagree" to questions 8, 10, and 17 were categorized as having high levels of medical mistrust. In other words, a low mean score for items 8, 10, 17 and a high mean score for item 9 indicate high levels of medical mistrust. Conversely, a high mean score for items 8, 10, 17 and a low mean score item 9 indicates low levels of medical mistrust.

Government Mistrust

To assess government mistrust, participants responded to items 11 (I believe COVID-19 was created in a lab) and 13 (The government is hiding information about COVID-19). A high mean score for items 11 & 13 indicates high levels of government mistrust while low mean score indicates low levels of government mistrust. These items were adopted from a study examining medical mistrust because of COVID-19: "The government is hiding information about COVID-19, When it comes to COVID-19, the government is lying to us, COVID-19 is manmade" (Bogart et al., 2021).

African American Acculturation Scale-Revised (AAAS-R)

Given that we wanted to investigate whether identification with the United States Black/African American culture indicates higher feelings of mistrust, we included the Interracial Attitudes subscale of the revised African American Acculturation Scale (AAAS-R) (Klonoff & Landrine, 2000). The AAAS-R is a 47-item questionnaire that assesses an individual's adherence to Black culture on 8 dimensions - Religious Beliefs & Practices, Preference for Things African American, Interracial Attitudes, Family Practices, Health Beliefs & Practices, Cultural Superstitions, Segregation, and Family Values. This subscale of AAAS helped identify to the extent a participant identifies with traditional African American culture. Seven questions were used from factor 3 (Interracial Attitudes) of the African American Acculturation Scale survey. These seven questions used are as follows: "Most tests (like the SATs and tests to get a job) are set up to make sure that Black people don't get high scores on them", "Deep in their hearts, most White people are racists", "IQ tests were set up purposefully to discriminate against Black people", "White people don't understand Black people", "Some members of my family hate or distrust White people", "I don't trust most White people", and "Most White people are afraid of

Black people"(Klonoff & Landrine, 2000). Participants had to respond to these seven questions using a 7-point Likert scale from 1 (I Totally Disagree Not True at All) to 7 (I Strongly Agree Absolutely True). This subscale has a Cronbach's alpha reliability score of .87 (Klonoff & Landrine, 2000). A high score on the AAAS-R scale means a high immersion in African American culture while a low score indicates a low immersion in African American culture.

Free Response

Part of the survey included a free response section where participants were asked the following question: "If you were hesitant to receive the COVID-19 vaccine, please explain why (open answer)". 20 participants answered the free response section and responses were reviewed by the primary investigator.

COVID-19 Information Sources

To assess where people received their information regarding COVID-19, we included the following items in the survey: "I rely on my peers to give me information about COVID-19", "I rely on news outlets/social media to give me information about COVID-19", I rely on family members to give me information about COVID-19", and "I rely on my doctor to tell me information about COVID-19". Participants had to respond to these four questions using a 5-point Likert scale from 1 (Strongly Disagree) to 5 (Strongly Agree).

GAD-7

In order to understand the effect medical mistrust has on vaccine hesitancy, we wanted to limit any confounding factors. Therefore, we added the 7-item self-report Generalized Anxiety Disorder Assessment (GAD-7) to see whether individuals' anxiety levels affected their vaccine hesitancy (*Generalized Anxiety Disorder 7-Item (GAD-7) - Mental Disorders Screening - National HIV Curriculum*, 2015). Participants had to respond to these 7 questions using a 4-point

Likert scale from 0 (not at all) to 3 (nearly every day). The score range is from 0 – 21 with higher scores indicating anxiety.

Data Analysis

While data from 53 participants were used for the subsequent analyses, 12 participants had incomplete surveys due to one or more unanswered questions. However, no participants were excluded from the study. Our main research hypothesis was that medical mistrust is associated with vaccine hesitancy. Therefore, we broke down the participant pool into two groups – those who are vaccine hesitant and those who are not vaccine hesitant. A participant was labeled as vaccine hesitant if they responded "yes" to question "Were you hesitant to receive the vaccine?" We then compared each group's responses to the items in the survey that assessed medical mistrust by conducting independent-samples t tests. We then combined the 4 items that assessed medical mistrust and the 2 items that assessed government mistrust to create a new variable called overall mistrust. We then ran a chi square test of independence to assess the relationship between vaccine hesitancy and medical mistrust. Overall mistrust was analyzed as a discrete variable. Any participant who endorsed mistrust for at least one of the 6 variables aimed to detect either medical or government mistrust was coded as a 1 and categorized as having mistrust. If a participant did not endorse any of the 6 variables, they were coded as 0, meaning no mistrust. The 6 variables used to detect medical and government mistrust were: "I trust the medical care system to keep me healthy", "When it comes to COVID-19, I cannot trust my healthcare providers", "When it comes to COVID-19, doctors have my best interests in mind", "I believe COVID -19 was created in a lab", and "The government is hiding information about COVID-19". For the free response section, we read through the 20 participants' answers and included the

statements that acknowledged the historical precedent and contemporary experiences of differential treatment based on racial identity in the medical institution.

Results

The demographic information of the participants can be seen in Table 1 below.

TABLE 1

Sociodemographic Characteristics

	n	%
Age in years		
18-20	7	13.5
21-29	12	23.1
30-39	6	11.5
40-49	4	7.7
50-59	11	21.2
60+	12	23.1
Gender Identity		
Male	18	35.3
Woman	33	64.7
Transgender	-	-
Non-binary	-	-
Prefer not to disclose	-	-
Other	-	-
Education level		
Never attended school or only attended Kindergarten	-	-
Elementary school/partial high school	1	2
High school degree or equivalent	7	13.7
Some college (no degree)	14	27.5
Associate or technical degree	6	11.8
University degree, bachelor level or equivalent	12	23.5
Post-graduate degree	11	21.6
Nativity Status		
U.S. Born	28	54.9
Foreign Born	23	45.1

In the study sample, 86.8% of participants received the COVID-19 vaccine despite 50% of participants expressing vaccine hesitancy. Compared to those who were not vaccine hesitant, respondents who were vaccine hesitant reported lower rates of trust in the medical care system (M = 2.77 , SD = 1.18; $t=4.15$, $p<0.001$). We also found that respondents who were vaccine hesitant reported higher rates of distrust in their healthcare providers (M = 2.42, SD = 1.02; t= -3.11, p <0.05). Participants in the vaccine hesitant group expressed more mistrust towards their doctors when it comes to COVID-19 (M=3.11, SD=0.99; $t(38.32) = 5.22$, $p < .0001$) whereas participants in the not vaccine hesitant group, were more trusting of their doctors (M= 4.23, SD=0.53; t = 5.22, $p < .0001$.) We also found that respondents in the vaccine hesitant group were more hesitant to rely on their doctor for COVID-19 information (M=3.07, SD=1.32; t = 3.40, p <0.05) whereas participants in the not vaccine hesitant group, had higher odds of relying on their doctor to tell them information about COVID-19 (M= 4.11, SD=0.82; t= 5.22, $p < 0.05$). Individuals in the vaccine hesitant group were more likely to rely on the news and social media outlets to receive COVID-19 information and less likely to rely on their doctors for COVID-19 information. On the other hand, people who were not vaccine hesitant, had a higher reliance on their doctors. When we looked at the vaccine hesitant and not vaccine hesitant groups and their beliefs on whether COVID-19 was created in a lab or not, the results were not significantly different. Participants in the vaccine hesitant group endorsed the belief that the government is hiding information about COVID-19 more than participants in the not vaccine hesitant group (M=3.54, SD=1.14), t = -3.41, p <0.05).

When we assessed the relationship between vaccine hesitancy and medical mistrust, we found a significant relationship between medical mistrust and vaccine hesitancy [X^2 (1, N = 53) = 5.03, p = .025]. Our second hypothesis was that higher identification with the United States

Black/AA culture would indicate higher feelings of mistrust. There was no significant difference between those with hesitancy versus without in identification with traditional African American culture ($M=29.4$, $SD=10.8$, $p>0.05$) and identification with African American culture was not correlated with overall mistrust in this sample ($p>0.05$).

When we looked at the qualitative data, we found that participants explicitly or subtly referred to discrimination in the healthcare setting as reasons for their hesitancy. They offered historical examples of personal anecdotes detailing instances of prejudice. One of the respondents wrote: “Historical medical ramifications of racism and sexism that have meant and presently mean that as black, queer woman, not trusting medical institutions and practitioners (or just being constantly wary of them) is a wise, data informed position”. Another respondent specifically referenced Tuskegee in her response: “Because of history of adverse testing on Black people. e.g. syphilis”. One participant stated that she was “kind of hesitant to trust providers in the US. I am an international student, so my trust for healthcare providers changes by country”.

Discussion

Vaccinations are an effective public health measure to mitigate and stop the spread of diseases like chicken pox, measles, whooping cough, etc (Dubé et al., 2013). However, when individuals are unvaccinated, their decision not only affects them, but the larger community by inhibiting successful herd immunity. The need to understand the extent and impact of vaccine hesitancy is a public health necessity which is why the objective of this study was to contextualize individual-level determinants of COVID-19 such as medical mistrust and its relationship to vaccine hesitancy. Medical mistrust is the culmination of years of systemic racism coupled with everyday acts of discrimination experienced by people of color. This eroded

relationship directly impacts how Black adults choose to engage and participate within the healthcare system.

When individuals harbor feelings of mistrust towards the medical institution, they are less likely to have faith in and trust health care professionals which translates into what we see now with the Black community and the low levels of COVID-19 vaccine compliance (Tram et al., 2021). Our results revealed a significant relationship between vaccine hesitancy and medical mistrust. Additionally, our findings support the existing literature that states when people have medical mistrust, they are more likely to be distrustful of their healthcare providers, which makes them not trust these medical professionals' advice. We found that respondents who were vaccine hesitant were less likely to trust their healthcare providers and expressed more mistrust towards their doctors. In the free response section, one participant stated that her COVID-19 vaccine hesitance stems from her knowledge of structural racism and the ways in which her positionality as a queer woman of color makes her vulnerable and open to prejudice in institutional and interpersonal settings.

In this study, we also observed that just because someone is vaccine hesitant does not mean that they will reject vaccination. While most subjects were vaccinated, we must highlight that 47% of participants were required to get vaccinated by their employer/institution. While vaccine hesitancy may not immediately equate to vaccination rejection, vaccine hesitancy can indicate and show us peoples' trusted sources of information. We found that individuals in the vaccine hesitant group were more likely to rely on news and social media outlets to receive information and less likely to rely on their doctors for COVID-19 information. The second hypothesis stated an association with identification with Black/African American culture and medical mistrust and our data revealed that vaccine hesitancy is not indicative of identification with Black culture.

Medical mistrust and vaccine hesitancy should not be seen as the fault of the individual, but rather the focus should be on the flawed medical institutions that consistently fail Black and Brown communities, thus contributing to the degradation of trust between physician and patient.

Future research should look at the unique aspects of Coronavirus-19 such as its highly politicized nature and analyze the role of the political climate played in individuals' hesitancy. Vaccine hesitancy is not a simple process; it is a complex and symbiotic decision-making process reinforced and influenced by the external social and political environment and one's own personal cognitions and beliefs regarding vaccination. During the height of COVID-19, many news articles discussed the numerous conspiracy beliefs that circled around the virus that further contributed to vaccine hesitancy. In the free response section, we saw some participants allude to such conspiracies; one of the participants said she was hesitant for "Political reasons but when the new administration took over, I felt safe". These conspiracies with preexisting medical mistrust led to 34% of Black people believing that COVID-19 was man made compared to 26% of White people (Bogart et al., 2021). Future research should further study the difference between medical mistrust and government mistrust to decide whether one is a stronger predictor of vaccine hesitancy. It would also be an interesting direction to open the study and include anyone who identifies as a racial minority in the United States. The Group-based Medical Mistrust Scale (GBMMS) would also be an important addition as it is specifically used to measure race-based medical mistrust (Thompson et al., 2004). Understanding the way in which medical mistrust potentially impacts individuals' decisions on whether to receive the COVID-19 vaccine is essential to ensure a healthy population. Oftentimes, there is a veiled sense of blame cast upon Black/African Americans which makes it challenging to see the fundamental causes of vaccine hesitancy. Addressing this health disparity involves an intentional investigation of the

social structures that uphold and perpetuate such inequities. Contextualizing vaccine hesitancy and reframing it as an outcome of medical mistrust can help public health officials implement effective strategies to market the COVID-19 vaccine in a culturally competent manner. Furthermore, we must contextualize medical mistrust as a justified response to an inherently unjust system- a way in which Black/African Americans choose to protect themselves from further harm at the hands of medical institutions. The existence of racism begets the existence of medical mistrust. By understanding the value and functionality of medical mistrust, healthcare professionals and large-scale organizations can create and develop the necessary solutions to rebuild and reestablish the trust between providers and their Black patients.

Limitations

The present study contributes to the body of literature about vaccine hesitancy and medical mistrust. However, there are limitations to this study. The first resides in the small sampling size which inhibited the types of statistical analyses we could run, making it more challenging to find discernible effects. Secondly, the survey used to assess attitudes and beliefs towards COVID-19, medical mistrust, and identification with African American culture were self-report measures, which carry inherent constraints like response bias. We also must be cognizant that as participants complete self-report measures, they are susceptible to the social desirability bias which can also impact the results collected from the study.

Conclusion

People experience vaccine hesitancy for a variety of reasons, and we must further investigate the driving forces that contribute to and fuel these feelings of hesitancy. By looking at

medical mistrust and the role it plays in the physician provider relationship for Black people, we can understand not only vaccine hesitancy, but the other negative outcomes that emerge from medical mistrust. Additionally, we can work towards mitigating the precursors to medical mistrust (such as interpersonal level discrimination) so that Black/African Americans do not have to utilize medical mistrust as a coping mechanism. Furthermore, additional work in this area may prove essential for effective marketing and messaging regarding the COVID-19 vaccine and begin the necessary groundwork to repair the trust between the medical system and people of color.

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Appendix A

Survey used to assess participants' beliefs and attitudes towards COVID-19, medical mistrust

The research is being conducted by Lian Nicholson, a graduate student at the University of Chicago, under the guidance of Dr. Marcia Tan, Assistant Professor in the department of public health services at the University of Chicago. In this survey, you will be asked to complete a series of questions about the COVID-19 vaccine. The purpose of this questionnaire is to investigate the factors that encourage or discourage individuals from getting the COVID-19 vaccine. Participants will answer a series of questions about their thoughts on the COVID-19 vaccine. The questionnaire should take approximately 10 minutes. The data will be used to gain insight on what variables impact whether an individual decides to receive the COVID-19 vaccine.

This study is minimal risk to participants; participants may experience discomfort answering questions pertaining to their personal beliefs and social identity. All data will be stored in a private and password protected area. Participants will be identified only by a unique subject number, and all data will be de-identified. Research participation is voluntary (and will not influence grades, employment, or career advancement). If you have any questions of concerns about our research study, we can be reached by email at liann@uchicago.edu.

If you agree to participate in this survey, please turn to the next page

Date: _____

In this section, our goal is to better understand the factors that encourage and discourage individuals' from getting the COVID-19 vaccine. As a reminder, all of your answers will be confidential.

1. Have you received the COVID-19 vaccine (at least one dose)?
   - ☐ Yes
   - ☐ Yes, but I did not want to
   - ☐ No
   - ☐ Not yet, but I will soon
   - ☐ No, but I want to
   - ☐ No and I do not plan on getting the vaccine

2. As soon as you were eligible to receive the vaccine (able to get an appointment, register, etc, did you get it immediately)?
   - ☐ Yes
   - ☐ No

3. Were you required to get the vaccine by an employer/institution?
   - ☐ Yes
   - ☐ No

4. Were you hesitant to receive the vaccine?
   - ☐ Yes
   - ☐ No

5. Were you excited to receive the vaccine?
   - ☐ Yes
   - ☐ No

Please rate the following statements:

6. People of color should delay getting the covid-19 vaccine.
   (1) Strongly disagree
   (2) Disagree

(3) Neither agree nor disagree
(4) Agree
(5) Strongly agree

7. White people should delay getting the covid-19 vaccine.
(1) Strongly disagree
(2) Disagree
(3) Neither agree nor disagree
(4) Agree
(5) Strongly agree

8. I trust the medical care system to keep me healthy.
(1) Strongly disagree
(2) Disagree
(3) Neither agree nor disagree
(4) Agree
(5) Strongly agree

9. When it comes to COVID-19, I cannot trust my healthcare providers.
(1) Strongly disagree
(2) Disagree
(3) Neither agree nor disagree
(4) Agree
(5) Strongly agree

10. When it comes to COVID-19, doctors have my best interests in mind.
(1) Strongly disagree
(2) Disagree
(3) Neither agree nor disagree
(4) Agree
(5) Strongly agree

11. I believe COVID-19 was created in a lab.
(1) Strongly disagree
(2) Disagree
(3) Neither agree nor disagree
(4) Agree
(5) Strongly agree

12. I am worried the covid-19 vaccine could be harmful to my health.
(1) Strongly disagree
(2) Disagree
(3) Neither agree nor disagree
(4) Agree
(5) Strongly agree

13. The government is hiding information about COVID-19.
    (1) Strongly disagree
    (2) Disagree
    (3) Neither agree nor disagree
    (4) Agree
    (5) Strongly agree

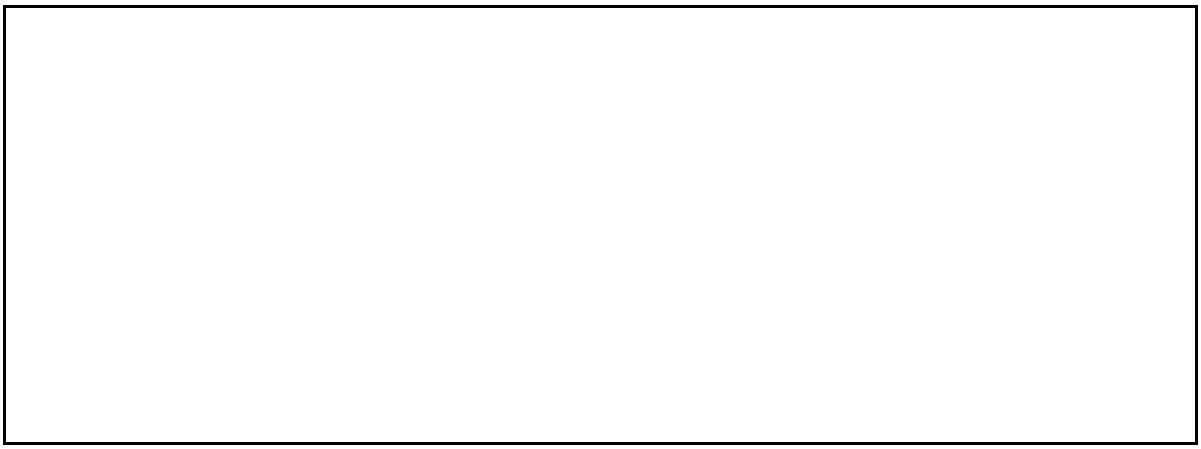
14. I rely on my peers to give me information about COVID-19.
    (1) Strongly disagree
    (2) Disagree
    (3) Neither agree nor disagree
    (4) Agree
    (5) Strongly agree

15. I rely on news outlets/social media to give me information about COVID-19.
    (1) Strongly disagree
    (2) Disagree
    (3) Neither agree nor disagree
    (4) Agree
    (5) Strongly agree

16. I rely on family members to give me information about COVID-19.
    (1) Strongly disagree
    (2) Disagree
    (3) Neither agree nor disagree
    (4) Agree
    (5) Strongly agree

17. I rely on my doctor to tell me information about COVID-19.
    (1) Strongly disagree
    (2) Disagree
    (3) Neither agree nor disagree
    (4) Agree
    (5) Strongly agree

18. If you were hesitant to receive the COVID-19 vaccine, please explain why (open answer)



In this next section, we are interested in collecting information regarding your identity and experience as a person of color. These questions were adapted from the beliefs and attitudes survey (Klonoff &Landrine, 2000)

19. Most tests (like the SATs and tests to get a job) are set up to make sure that Black people don't get high scores on them.

I Totally Disagree Not True at All			***Sort of Agree, Sort of True***			***I Strongly Agree Absolutely True***
1	*2*	*3*	*4*	*5*	*6*	*7*

20. Deep in their hearts, most White people are racists.

I Totally Disagree Not True at All			***Sort of Agree, Sort of True***			***I Strongly Agree Absolutely True***
1	*2*	*3*	*4*	*5*	*6*	*7*

21. IQ tests were set up purposefully to discriminate against Black people.

I Totally Disagree Not True at All			***Sort of Agree, Sort of True***			***I Strongly Agree Absolutely True***
1	*2*	*3*	*4*	*5*	*6*	*7*

22. White people don't understand Black people

I Totally Disagree Not True at All			***Sort of Agree, Sort of True***			***I Strongly Agree Absolutely True***
1	*2*	*3*	*4*	*5*	*6*	*7*

23. Some members of my family hate or distrust White people

I Totally Disagree Not True at All			***Sort of Agree, Sort of True***			***I Strongly Agree Absolutely True***
1	*2*	*3*	*4*	*5*	*6*	*7*

24. I don't trust most White people

I Totally Disagree Not True at All True						*I Strongly Agree Absolutely*
1	*2*	*3*	*4*	*5*	*6*	*7*

25. Most White people are afraid of Black people

I Totally Disagree Not True at All True						*I Strongly Agree Absolutely*
1	*2*	*3*	*4*	*5*	*6*	*7*

Over the last 2 weeks, how often have you been bothered by any of the following problems?

26.Feeling nervous, anxious or on edge?
- (0) Not at all
- (1) Several days
- (2) More than half the days
- (3) Nearly every day

27. Not being able to stop or control worrying?
- (0) Not at all
- (1) Several days
- (2) More than half the days
- (3) Nearly every day

28. Worrying too much about different things?
- (0) Not at all
- (1) Several days
- (2) More than half the days
- (3) Nearly every day

29. Trouble relaxing?
- (0) Not at all
- (1) Several days
- (2) More than half the days
- (3) Nearly every day

30. Being so restless that it is hard to sit still?
- (0) Not at all
- (1) Several days
- (2) More than half the days
- (3) Nearly every day

31. Becoming easily annoyed or irritable?
- (0) Not at all
- (1) Several days
- (2) More than half the days
- (3) Nearly every day

32. Feeling afraid as if something awful might happen?
    (0) Not at all
    (1) Several days
    (2) More than half the days
    (3) Nearly every day

In this last section, we would like to collect demographic information

33. What is your age?
    - ☐ 18-20
    - ☐ 21-29
    - ☐ 30-39
    - ☐ 40-49
    - ☐ 50-59
    - ☐ 60+

34. What is your race/ethnicity? Please select all that apply
    - ☐ White
    - ☐ Black/African American
    - ☐ American Indian/Alaskan Native
    - ☐ Middle Eastern or North African
    - ☐ Latin(x) or Hispanic
    - ☐ Asian
    - ☐ Native Hawaiian or Pacific Islander
    - ☐ Other _____

35. What is the highest level of education you achieved?
    - ☐ Never attended school or only attended Kindergarten
    - ☐ Elementary school or partial high school
    - ☐ High school degree or equivalent (grade 12 or GED)
    - ☐ Some college (no degree)
    - ☐ Associate or technical degree
    - ☐ University degree, bachelor level or equivalent
    - ☐ Post-graduate degree

36. Were you born in the United States?
    - ☐ Yes
    - ☐ No

37. What is your current zip code?

    _____

38. How do you identify?
    - ☐ Woman
    - ☐ Man
    - ☐ Transgender
    - ☐ Non-binary

- ☐ Prefer not to disclose
- ☐ Other _____