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## **"Buried in the Bones": Medical Racial Trauma and Mistrust in Black Families**

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# **“BURIED IN THE BONES”: MEDICAL RACIAL TRAUMA AND MISTRUST IN BLACK FAMILIES**

A Thesis

Submitted to the Graduate Faculty of the  
Louisiana State University and  
Agricultural and Mechanical College  
in partial fulfillment of the  
requirements for the degree of  
Master of Science

in

Deptment of Social Work

by  
Destiny Jelks  
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## Table of Contents

|   |    |
|---|----|
| Abstract .....  | 2  |
| Chapter 1. Introduction .....                         | 3  |
| Chapter 2. Review of Literature .....                 | 9  |
| Chapter 3. Methodology .....                          | 19 |
| Chapter 4. Results .....                              | 23 |
| Chapter 5. Discussion .....                           | 49 |
| Appendix A. Abbreviated Medical Mistrust Surevy ..... | 54 |
| Appendix B. Interview Questions .....                 | 61 |
| Appendix C. Consent Form .....                        | 62 |
| Appendix D. Demographic Questionnaire .....           | 64 |
| Appendix E. Recruitment Email .....                   | 65 |
| References.....                                       | 66 |
| Vita .....  | 72 |

## **Abstract**

This exploratory study used a mixed-methods design and phenomenological approach to examine the ways in which the United States' history of medical racism impacts Black young adults and their attitudes toward the healthcare system as well as healthcare utilization. This study examines the phenomenon through the lense of critical race theory, family systems theory, and historical trauma theory. This study also explored the concept of the intergenerational transmission of trauma focusing on medical racial trauma and medical mistrust in Black families.

## **Chapter 1. Introduction**

When discussing the topic of the intergenerational transmission of trauma, psychiatrist Franz Fanon believed “the negative impact of oppression to be so powerful, as to be buried in the bones of those who suffered it” (Vaughans, 2020, p. 565).

### *Historical Perspective*

Since being brought to the United States in the 1600s, Black people have been seen as the inferior race in White-dominated American society. There was a general belief amongst White physicians that Black people differed from White people biologically (Ford, 2019). This idea of Black difference and often inferiority was further supported by multiple theorists throughout history and contributed to a majority of the racist medical protocols and procedures that have been seen. According to Benjamin Rush, one of the men who signed the Declaration of Independence, racial differences lay within what he called Negritude which was defined as a disorder that all Black people possessed because of their dark skin (Ford, 2019). In the 1800s, Georges Cuvier built on this theory with the idea of polygenesis, which is the idea that races have different origins (Ford, 2019). With this theory, races were placed in categories based on their civilization and skull quality with White people placed at the top and Black people at the very bottom of the hierarchy (Ford, 2019). The Black race was also considered to be relatively close to monkeys and barbaric under Cuvier's theory. Another supporter of scientific racism, Josiah Nott, believed that Black people had a much higher pain and stress tolerance than White people. Nott and other individuals at that time also believed that Black people were inferior and because of this the basic rules of humanity did not apply to them (Ford, 2019). All of these beliefs paired with over 200 years of slavery and a lack of resources and education have shaped

what is known as modern medicine in the United States. They have led to numerous incidents of immoral experiments on Black bodies as well as medical mistreatment.

### *Theoretical Perspective*

This study will be conducted through the lens of multiple theories. The first theory is critical race theory. Critical race theory can be employed to understand racialized experiences and perceived discrimination. Delgado and Stefancic (2017) provide several tenets of critical race theory. The first tenet of critical race theory is that race is socially constructed, not biological. Race is a construct that is manipulated as society sees fit (Delgado & Stefancic, 2017). The second tenet of critical race theory is racism is normal and a common experience for people of color. The idea of mundane extreme environmental stress, or MEES, falls under this tenet. Though racism is a common experience for many Black people, the environment caused by racism and subtle oppression is described as “ubiquitous, constant, continuing, and mundane” (Carroll, 1998, p. 271). This environment is extremely harmful and can cause individuals stress (Carroll, 1998). The third tenet of critical race theory is interest convergence or material determinism. This tenet suggests that the legal system in the United States works in the best interest of White citizens while further disadvantaging individuals of color. The fourth tenet of critical race theory is differential racialization. This is the attribution of negative stereotypes to racial groups based on the interests of White people. The fifth tenet is the idea of intersectionality, “no person has a single, easily stated, unitary identity” (Delgado & Stefancic, 2017, p. 9). The sixth and final tenet of critical race theory is the idea of a unique voice of color. This suggests that all people of color are qualified to speak on behalf of their racial group.

Another theory used for this study is family systems theory. Family systems theory, created by American psychiatrist Murray Bowen, suggests that members of a family are interdependent, with each family member influencing and being influenced by one another

(Fitzgerald et al., 2020). How a family functions impacts its members and its members impact the function of the family system. Family systems theory also focuses on patterns in families across generations. Bowen's family therapy is considered to be a multigenerational transmission process (Helm, 2021). Though interdependence varies in each family, all families have some level of interdependence. This means that every individual, close to their family or not, is impacted by their family system.

The final theory used for this study is historical trauma theory. Historical trauma is caused by a cumulative traumatic experience that has a lasting impact across generations which leads to a collective group experience (Brave Heart, 2003). This means that a person belonging to a cultural group that has had a history of oppression and trauma may be indirectly affected by these experiences. According to Sotero (2006), there are three phases of historical trauma. The first phase is where the dominant group inflicts mass trauma on the marginalized group. Examples of mass traumas include genocide, displacement, and slavery. During the second phase, the marginalized group experiences a psychological response to the trauma that can also impact them physiologically and socially. The third and final phase involves later generations being negatively impacted by the trauma their ancestors endured.

### *Purpose of the Study*

The history of racism and medical mistreatment in the United States has impacted the Black community in multiple ways. Though the participants of this study will be generations removed from directly experiencing the instances of medical racism that will be discussed, the goal of this study is to determine how medical racial trauma has been transmitted intergenerationally. This exploratory study used a mixed-methods design and phenomenological approach to examine the ways in which the United States' history of medical racism impacts

Black young adults and their attitudes toward the healthcare system as well as healthcare utilization.

In this study, medical racism is defined as prejudice and/or discrimination based on race in the medical context. This includes factors such as negative attitudes of healthcare professionals towards a specific race, medical mistreatment, unethical experimentation, unequal access to healthcare, and lower quality care (Nuddrin et al., 2020). Medical mistrust is one of the effects of experiencing medical racism (Peek et al., 2010).

### *Assumptions*

There are three assumptions that guided this study. The first assumption is that contemporary young Black adults are aware of the history of medical racism in the United States. The researcher made this assumption based off their awareness of the history of medical racism as well as previous conversations with other young Black adults surrounding the topic. The literature review of this study includes several examples of medical racism that the researcher was knowledgeable about prior to conducting the study. The second assumption the researcher brought into this study is that Black families discuss the history of medical racism in the United States. This assumption is held because of the researchers prior knowledge of racial socialization, the process in which parents teach their children about race and what it means to belong to a minority group (Blanchard et al., 2018). The third and final assumption the researcher made is that the familial conversations surrounding the history of medical racism in the United States have impacted young Black adults. It was assumed that this factor impacts the medical mistrust levels and healthcare utilization of young Black adults.

### *The Researcher*



I brought to this research my current experience of being a young Black woman who has to navigate the healthcare system in the United States while also being very aware of the long history of medical racism. Though I have not personally experienced medical racism, I have reason to believe that it is still a public health issue in the United States. I have heard and seen countless stories and examples of medical racism from the past as well as current. Additionally, have been a part of familial conversations that involve warnings about healthcare providers and urging me to try and only visit those who are also Black women.

I obtained my undergraduate degree in Psychology from Spelman College, a historically Black all-women's college. During my time at Spelman, I took classes such as African Diaspora and the World, Psychology of Racism, and Black Female Body in Visual Arts. These classes and more provided me with a rich background in Black American history as well as the history of the Black diaspora overall. They also made me conscious of the impact racism has had on Black people. Since I have been pursuing my master's degree in Child and Family Studies from Louisiana State University, I have chosen to focus majority of my research on intergenerational transmission in families. I conducted a previous study examining the intergenerational transmission of parenting styles. This study also focused on young adults, specifically young mothers. My interests in exploring the impact of racism on the Black community and intergenerational transmission within families have lead me to research the intergenerational transmission of racial trauma in Black families.

Through firsthand experience, I have witnessed the impact of medical racism on the Black community and the intergenerational transmission of medical racial trauma. It is my hope that the data collected from this study can serve as a starting point for continuing research this phenomenon.

## **Chapter 2. Review of Literature**

### *The Tuskegee Syphilis Study*

When discussing the history of medical racism in the United States, one of the most cited examples is the Tuskegee Syphilis Study, which was launched in 1932 by the Public Health Service. During this time, doctors wanted to study the disease and the south was a breeding ground for it. According to Ford (2019), the highest number of cases of Syphilis was in Macon County in Tuskegee, Alabama, with 36% of the population having the disease. Syphilis was common amongst the Black population in the South. Though physicians at the time attributed this to Black people being innately promiscuous, this prevalence of syphilis was actually caused by poverty, lack of education, and poor living conditions (Ford, 2019). At that time, “most Black people were sharecroppers and as a result could not afford medical care as a doctor visit would cost \$12 and for those few who could afford a doctor, many white physicians didn’t serve Black patients” (Ford, 2019, p. 3). The lack of resources afforded to Black people compared to their White counterparts is something that has been a longstanding factor that contributes to medical racism and was seen in the Tuskegee Syphilis Study. This study consisted of 400 Black men from Tuskegee, Alabama who already had syphilis. The physicians involved recruited these men with the promise of free healthcare, but these men did not know the true details of the study. The physicians’ goal was to see how syphilis affected the Black body over time and especially in death. In order to achieve this, instead of treating the men for the disease the physicians administered placebos and told them they were being treated for “bad blood” though treatment was available (Ford, 2019). This experimentation was deemed acceptable at the time because Black people were not really seen as human and were thought to have a higher tolerance to diseases like syphilis. It was also believed that syphilis affected Black and White individuals

differently because they were biologically different. Since the physicians were interested in the death caused by syphilis, they allowed the bodies of these Black patients to be ravaged by the disease in order to study the bodies after death (Ford, 2019). This experiment lasted well after the development of penicillin in 1942 and without the true consent and knowledge of the Black patients involved.

### *Gynecology*

The widespread belief that Black people were immune to pain and could be used for medical experimentation also led to what is known as gynecology today. James Marion Sims, who is known as the founder of gynecology, arrived at many of his medical discoveries through his exploitation and experimentation on enslaved Black women in the nineteenth century. The bodies of these enslaved women were seen as “anatomical material” and dispensable once experimentation was complete (Nuriddin et al., 2020). Sims would perform excruciating procedures on enslaved women with no anesthesia or proper aftercare. It was only once he perfected these procedures did he attempt them on White people with anesthesia and proper after-care. One enslaved girl, seventeen-year-old Anarcha, was operated on thirty times in an effort to perfect his fistula surgery. It is recorded that Sims forced the girl “kneel in agony while he inserted a speculum into her vagina and attempted to close ravaged openings by abrading their edges before suturing. Other whites held Anarcha as she screamed” (Feagin & Bennedield, 2013, p. 9). Not only did Sims experiment on enslaved women he also performed procedures on Black children. It is recorded that he would use shoemaker tools to pry apart the bones and loosen the skulls of Black children (Holland, 2017).

### *Eugenics and Involuntary Sterilization*

In the 20th century hundreds of Black women, more probably undocumented, reported they were victims of involuntary sterilization and hysterectomies. One known case of this was civil rights leader Fannie Lou Hamer, who in 1961 went to have a uterine tumor removed and was instead given a hysterectomy. When she asked the physician why he would do that to her, she never received an answer but was instead silenced (Feagin & Bennefield, 2013). Cases like these continued to occur and were backed up by eugenics. According to Washington (2006), “eugenics was appropriated to label Black women as sexually indiscriminate and as bad mothers who were constrained by biology to give birth to defective children” (p. 191). Though this stereotype of Black women had been around for years, eugenicists gave what they believed was biological and scientific evidence to support it (Feagin & Bennefield, 2013). In 1939 Margaret Sanger created the “Negro Project” intending to decrease the Black population through negative eugenics (Sanger, 1922). To achieve this, birth control was tested in Black communities. Due to the high levels of hormones in early birth control pills, Black women were subjected to harmful side effects such as: hypertension, stroke, infections, and more (Feagin & Bennefield, 2013). The United States government funded and supported eugenics and forced sterilization and countless numbers of Black women became victims.

### *HeLa Cells*

In 1951, Henrietta Lacks, a young Black mother of five, went to the segregated ward of John Hopkins hospital complaining of vaginal bleeding and was eventually diagnosed with cervical cancer. While she was being treated for cancer, samples of her cells were taken without consent. Her physicians then chose to discontinue her radiation treatment and switch to antibiotics because they believed she just had a venereal disease and not cancer (Feagin & Bennefield, 2013). Due to the malpractice, Lacks succumbed to her condition and passed away.

The cells that were collected were given to Dr. George Grey and he discovered that Lacks' cells were like no other he had seen before. Normal cells would die, but hers doubled every twenty to twenty-four hours. Grey went on to mass-produce Lacks' cells for profit. What was originally a woman seeking cancer treatment was turned into a multi-billion dollar industry. Since their discovery Lacks' cells have been used in the advancement of many medical research areas "including immunology, oncology, and the development of the polio vaccine" (Nuriddin et al., 2020, p. 950). Though Lacks received posthumous acknowledgment years later, her family has never been financially compensated for her contribution to medicine.

### *Effects of Medical Racism*

Though there has been some progress made in eradicating medical racism in the United States, the effects of the country's long history of discrimination, abusive experimentation, and mistreatment have had long-lasting effects on the Black population. Racism has played a significant role in the development of medical practices and procedures, and though it is now considered taboo, the remnants of it still remain. The persistence of racism in medical care has currently manifested itself in multiple ways including Black people being reluctant to receive treatment, Black people not receiving the proper treatment, and higher death rates for Black people (Feagin & Bennefield, 2013; Ginty, 2005; Mayberry et al., 2000; Alexander & Sehgal, 1998).

One major effect of medical racism is medical mistrust. Medical mistrust involves feelings of mistrust toward medical professionals and the healthcare system overall. According to Sanford and Clifton (2021), medical mistrust is "the extent to which a person has fears of being harmed by medical care, doubts about the accuracy or value of information from medical authorities, or questions about the integrity or motives of medical authorities" (p. 10). Medical

mistrust can also include mistrust of specific diseases. A recent example of medical mistrust of a disease has been evident in the COVID-19 pandemic (Smith et al., 2021). Peek et al. (2010) suggests that medical mistrust can occur following experiences of racial discrimination. Because of this, studies have shown that levels of medical mistrust tend to be higher among Black people than their White counterparts (Armstrong et al., 2008; LaVeist et al., 2000). These higher levels of mistrust are associated with negative health-related outcomes such as lower care satisfaction, delayed checkups and screenings, and lower adherence to medical treatment (Powell et al., 2019). Medical mistrust is also associated with reluctance or refusal to participate in medical research and organ donation (Sanford & Clifton, 2021; Morgan, 2004).

Another effect of medical racism is racial trauma. According to the American Public Health Association, racism is considered to be a public health crisis (American Public Health Association, 2020). When racism is experienced, it can cause race-based stress (Hargons, 2021). Some examples of race-based stressors include violence, discrimination, and microaggressions. Prolonged exposure to race-based stressors, can lead to race-based traumatic stress, which is defined as “the psychophysiological injury one experiences when witnessing or encountering a racist situation” (Hargons et al., 2022, p. 50). Racial trauma occurs in severe cases of race-related stress (Carter, 2007). Previous studies have been done to examine the severity of racial trauma. One study showed that racial trauma is similar to the trauma caused by other traumatic experiences such as rape and domestic violence (Bryant-Davis & Ocampo, 2005). It has also been found that racial trauma can lead to acute stress symptoms as well as post-traumatic stress disorder in people of color (Carter et al., 2005). According to Pinderhighes (2004), “at a personal level the trauma to African Americans caused them to have an inner life of repeated fear and

terror, death anxiety, psychic numbing, disconnection, isolation, tendency to self-sacrifice and self-denigration” (p. 165).

### *Intergenerational Transmission of Trauma*

Traumatic is just one of the words that can be used to describe the Black experience in the United States. Though some of these injustices happened long ago, they have long-lasting implications. Medical racism can be considered a historical trauma since it has impacted the Black community collectively and over the span of many years. The specific definition of Black historical trauma is “the collective spiritual, psychological, emotional, and cognitive distress perpetuated intergenerationally deriving from multiple denigrating experiences originating with slavery and continuing with pattern forms of racism and discrimination to the present day” (Hampton et al., 2010, p. 32). Other examples of historical traumas experienced by the Black community are slavery, segregation, and numerous massacres, riots, and instances of police brutality (Henderson et al., 2021; Davis, 2022; Williams-Washington & Mills, 2017). This historical trauma, when remembered by members of Black community, can lead to race-based stress and racial trauma (Hargons, 2021). Since historical trauma can affect multiple generations, it supports the idea of the intergenerational transmission of trauma.

Intergenerational transmission of trauma is also supported by family systems theory. Since the lives of family members are connected and interdependent, circumstances that affect one member can affect others through direct and indirect interactions (Fitzgerald et al., 2020). The traumatic experiences of one family member can be transmitted to later generations through the compromised family functioning caused by the trauma (Pinderhughes, 2004). Symptoms of the intergenerational transmission of trauma include fear, mistrust, and more (Kincade & Fox,

2020). Though later generations did not experience these traumas, it has been suggested that they tend to “bear the scar without the wound” (Albeck, 1994).

The intergenerational transmission of trauma can occur through the process of racial socialization. Racial socialization is used to teach children about race/ethnicity. Through parents' explicit and implicit messages, children learn what being a member of a minority group means for them (Blanchard et al., 2018). For Black families, racial socialization often involves “discussions about racism, discrimination, coping behavior, and strategies to succeed in mainstream society” (Kincade & Fox, 2020, p. 222). According to Hughes et al. (2006), some of the tenets of racial socialization include preparation for bias and promotion of mistrust. Through the tenet preparation for bias, also known as racism preparation, parents teach their kids about their minority status and what it means in a white-dominated society. Not only do parents help their children become conscious of their race, but they must also prepare them to handle racially charged situations (Blanchard et al., 2018). Through the tenet promotion of mistrust, Black parents teach their children “to be cautious in white contexts and in interactions with white people” (Blanchard et al., 2018, p. 389). This tenet of racial socialization is visible when Black parents share historical and personal instances of racism with their children. This form of storytelling and warning not only helps protect Black youth from negative racial experiences but also helps prevent them from being in those situations, to begin with.

### *Previous Studies*

Though there is a lack of previous research done on the intergenerational transmission of trauma in Black families, there has been previous research done on the descendants of Holocaust survivors. According to Berger (2014), “the trauma of the Holocaust overwhelmed and debilitated the boundaries, authority structure, and roles within families that had been established



and developed over the course of centuries” (p. 174). Studies have shown the negative psychological effects of being parented by individuals who have experienced collectively traumatic events (Sigal, 1989; Bergmann & Jucovy, 1982). Some of the effects include the inability to separate from parents, anxiety, problems controlling aggression, and identity problems.

Previous research within the Black community that has been done on the intergenerational transmission of trauma focused on the fear of police brutality. In the United States, Black Americans “are more likely to be stopped, searched, arrested, and charged with more serious crimes” and also, are “killed by police at three times the rate of their white counterparts” (Kincade & Fox, 2020, p. 221). The results of Kincade and Fox (2020) suggest that the effects of negative encounters with the police are transmitted through generations. An example of intergenerational transmission as well as racial socialization in the context of police brutality is Black parents having “The Talk” with their children. “The Talk” is a conversation Black parents have with their children to prepare them for encounters with the police and other authority figures. According to Miller and Vittrup (2020), “it involves warnings of how they may be perceived by the police because of their skin color, as well as guidelines for how to behave in the presence of police in order to mitigate potential harm” (p. 1703). During this conversation, parents often stress the importance of being respectful when dealing with authority figures like the police (Miller & Vittrup, 2020). When preparing their children for bias, parents often share their own racialized experiences and injustices. They also share things they see in the news and media (Miller & Vittrup, 2020). Some parents feel the need to go further and provide their children with step-by-step instructions on how to survive encounters with police (Miller & Vittrup, 2020). This parent-child discussion is important because studies have shown that Black

children are typically perceived as older and more dangerous due to racial bias. They are also more likely than their white counterparts to be seen as guilty and to become victims of police violence. Black children are more likely to become victims of police brutality than white children (Goff et al., 2014). In the Obel-Omia (2016) study, young black boys reported feelings of fear and uneasiness regarding police as well as the belief that society views them as a threat. Black parents live in fear that their children's encounters with police can potentially end in death (Miller & Vittrup, 2020). Sharing these warnings is a survival tactic that Black parents have adopted and feel they must employ in an attempt to keep their children safe. Feelings of fear and mistrust are developed through direct and indirect experiences with the police.

## **Research Questions**

How an individual was raised has a significant influence on their development as well as their views and choices later in life. One thing that is possibly affected is how much individuals trust the healthcare system in the United States. Though literature is abundant on medical racism in the United States, there is not much on how parental views of medical racism and medical mistrust affect their children. In response to the lack of previous research done on this topic, this study posed and responded to the following questions.

1. How much do young Black adults trust the healthcare system in the United States?
2. How does the history of medical racism in the United States affect the attitudes towards healthcare of young Black adults?
3. How have the views of their families affected young Black adults' current levels of medical mistrust?
4. How does medical mistrust impact healthcare utilization?
5. How do direct experiences with medical racism impact young Black adult healthcare utilization?
6. How do indirect experiences with medical racism impact young Black adult healthcare utilization?
7. How do direct experiences with medical racism impact medical mistrust?
8. How do indirect experiences with medical racism impact medical mistrust?

### **Chapter 3. Methodology**

The purpose of this exploratory study was to identify the ways in which the United States' history of medical racism impacts contemporary Black young adults and their attitudes toward the healthcare system as well as healthcare utilization.

#### *Research Design*

A correlational research design was used to determine the relationship between medical mistrust and healthcare utilization, experiences with medical racism and healthcare utilization, and experiences with medical racism and levels of medical mistrust. This study used primary data collected through survey and interview. The *Medical Mistrust Survey* (2003) was used to determine levels of mistrust, healthcare utilization, and to record experiences with medical racism. A phenomenological approach was used to determine levels of medical mistrust as well as how the history of medical racism and familial views impact how young Black adults feel about the healthcare system in the United States. Interview questions were created based on questions in the *Medical Mistrust Survey* (2003).

#### *Sample*

Convenience sampling was used to recruit participants for this study. For this study, there were a total of 11 participants. All 11 of the participants completed the survey and 3 of the participants completed the follow-up interview. The participants consisted of Black young adults, aged 18-25 years old. Any individuals who were not Black or aged 18-25 years old were excluded from this study. They were students enrolled at a large public university located in a large southern city.

#### *Measures*

To conduct this study, an abbreviated and adapted version of the *Medical Mistrust Survey* (2003) created by the Johns Hopkins School of Public Health was used to determine participants' levels of medical mistrust. This survey consists of 7 sections and for this study, the following sections were used: Section B: medical mistrust index, Section C: healthcare utilization, Section D: negative experiences with the healthcare system, Section E: health behavior, and Section G: perceived racism index. Some examples of items from each section of the survey include:

B1. You'd better be cautious when dealing with healthcare organizations.

C20. If you could choose, would you prefer to be treated by a doctor of your own race or ethnic group, another race or ethnic group, or do you have no preference?

D1. Have you ever had a healthcare experience where you were physically harmed or mistreated?

E1. In the last two years, have you had a complete physical exam by a doctor or other health professional?

G3. In most hospitals, African Americans and whites receive the same kind of care.

[See Appendix A]

Following the phenomenological approach, participants were interviewed about their level of medical mistrust and how their parents or family has influenced it. The interview consisted of approximately 13 questions based on the participant's questionnaire responses. Some examples of interview questions include:

1. How do you feel your race has affected your medical experiences?
2. What conversations have your parents/guardians had with you regarding the healthcare system?
3. How does what you know about the history of medical racism in the US affect your trust in the healthcare system?

[See Appendix B]

### *Procedure*

The participants were obtained through a recruitment email. Once they agreed to participate in the study, the participants went to the Qualtrics link provided in the email. Prior to participating in the study, participants were required to sign a consent form that included any potential study risks. Once consent was given, participants were directed to the abbreviated version of the *Medical Mistrust Survey* (2003) and the demographic questionnaire. At the end of the survey and questionnaire, participants were asked if they would like to complete a follow-up interview for a chance to win a \$25 Amazon gift card. If they selected yes, they provided their email and were contacted for the interview and received a consent form to sign before the start of the interview. The interviews were held via Zoom and the meeting was recorded. Pseudonyms (Participant A, Participant B, and Participant C) were used in place of the names of the participants to maintain anonymity.

This study used a phenomenological approach to analyze the qualitative data. Following this approach, the phenomenon of medical racism was examined through the personal experiences of each participant. The goal of using this approach was to describe the experiences of contemporary young Black adults. To adhere to this goal, hypotheses were not created for the qualitative portion of this study, but the researcher acknowledged assumptions that were made regarding the study. The process used in the phenomenological approach involved 3 steps. First, bracketing was used to eliminate preconceived notions about medical racism and focus on the experiences of the three survey participants. During this step, the researcher acknowledged their prior knowledge of the phenomenon and made the conscious effort to remain impartial and not allow their prior knowledge to impact the study. An example of bracketing used in this study can

be seen in the order the researcher asked the research questions. The researcher placed broader topic questions at the beginning of the interview and those specifically about medical racism closer to the end. By not knowing the specific topic of the study until closer to the end of the interview, the interview participants were able to give non biased answers to questions like:

*What conversations have your parents/guardians had with you regarding the healthcare system?*

The goal of bracketing was to gain a fresh perspective pertaining to the phenomenon and focusing solely on the individual participant experiences (Ungvarsky, 2020). After bracketing, the researcher engaged in intuiting, which is the process of focusing on understanding the phenomenon through the lived experiences of the survey participants (Greening, 2019). The final step of the phenomenological approach was analyzing. During this step, the researcher coded the data collected by reviewing notes taken during the interviews to identify common themes among participant experiences in order to seek information about how medical racism impacts the current population of young Black adults in the United States (Lester, 1999).

## Chapter 4. Results

### *Participant Demographics*

Out of the 18 survey responses that were obtained, the results from the 11 that were completed were used. Demographic information collected on the participants included age and gender. All the participants identified as Black or African American. Ages of the participants ranged from 18-25 years, with there being approximately 27.3% of the participants aged 19 years old, 27.3% aged 20 years old, 9.1% aged 21 years old, 9.1% aged 22 years old, and 27.3% aged 25 years old. The majority of the participants, 90.9%, identified as female and 9.1% identified as non-binary. All the participants were students currently enrolled at a large public university located in a large southern city.

### *Quantitative Data Analysis*

To measure medical mistrust, a scale was created based on the statements in Section B: Medical Mistrust Index V2.2 Measuring Mistrust in Healthcare. The range of response categories were 1-4 with 1 (strongly disagree) being the lowest and 4 (strongly agree) being the highest. A mean score for each participant was calculated, creating a new variable, Medical Mistrust Mean. The researcher created a scale for assessing the level of medical mistrust. With a range of 1-4, scores that fell under 2.5 were considered to represent low levels of medical mistrust and scores that fell above 2.5 were considered to represent high levels of medical mistrust. Negatively worded items in Section B were reverse coded to ensure that they were consistent with the positively worded items in the section.

IBM SPSS29 was used to report the means of the quantitative data collected from the *Medical Mistrust Survey* (2003). IBM SPSS29 was also used to run Spearman *rho* rank correlation tests to determine how participants' personal experiences or experiences of those



close to them impacts their healthcare utilization as well as how participants' personal experiences or experiences of those close to them impacts their level of medical mistrust. Research questions four, five, six, seven, and eight were answered using quantitative data analysis. Significance levels for the correlational analyses were set at  $p < .05$ .

### *Qualitative Data Analysis*

Qualitative data was collected through interviews with the three survey participants who agreed to be interviewed. The three participants shared their experiences regarding their trust or mistrust of the healthcare system in the United States as well as personal, familial, and peer negative healthcare utilization experiences. Out of the interview participants, 2 identified as female and 1 identified as non-binary. The interviews were recorded for later review.

Themes that emerged from the interview and phenomenological analysis process included: medical mistrust, mistrust of non-Black doctors, racial trauma, historical trauma, intergenerational transmission, peer transmission, racial socialization, healthcare accessibility, and perseverance. These themes were based on participant responses and commonalities among them. Participants displayed these themes through their responses to the interview questions posed as well as through provided examples that supported their responses as well as their feelings towards the healthcare system in the United States. Research questions one through seven utilized participant interviews and phenomenological data analysis to answer the research questions. These themes will be discussed in more detail with the research questions.

### *Research Question 1: How much do young Black adults trust the healthcare system in the United States?*

This research question was answered using the qualitative interviews conducted with three of the survey participants. However, an overall measure of medical mistrust was calculated

for all survey participants. Section B: Medical Mistrust Index V2.2 Measuring Mistrust in Healthcare of the Medical Mistrust Survey (2003) provided scores that represent participant levels of mistrust. According to the medical mistrust scale that was created for this study, mean scores that fell under 2.5 were considered to represent low levels of medical mistrust and scores that fell above 2.5 were considered to represent high levels of medical mistrust. The mean scores of each participant were calculated and then the average of those scores were calculated. The overall average score of medical mistrust was 2.8. It was also found that 1 out of the 11 participants scored lower than the 2.5 cutoff and the other 10 scored above.

The theme related to Black adults' trust in the healthcare system in the United States included: mistrust of non-Black doctors. Each participant expressed similar points of view when asked the interview question: *How comfortable do you feel when going to the doctor?*

When asked about comfortability when visiting the doctor, Participant A reported that her level of comfort when visiting the doctor was an 8 out of 10. She further explained that her level of comfort was influenced by the fact that she had picked her own primary care physician and did research beforehand. She also noted that her primary care physician was also a Black female and that added to her level of comfort.

On a scale of 1-10, Participant B reported that their level of comfort when visiting the doctor was a 6. They further explained that their level of comfort was influenced by the fact that they have had some really good medical experiences. They also stated that their level of comfort often depends on the type of doctor they see as well as the context of the visit.

Participant C stated that her level of comfort depended on the race of the doctor. On a scale of 1-10, Participant C reported that her comfort level with a doctor who is a person of color

tends to be at 8 or 9. If the doctor is not a person of color, or specifically is a White male, Participant C's comfort level is a 6.

*Research Question 2: How does the history of medical racism in the United States affect the attitudes towards healthcare of young Black adults?*

This research question was also answered using the qualitative interviews conducted with three of the survey participants. Themes related to the history of medical racism in the United States and its effects on the attitudes towards the healthcare of young Black adults included: medical mistrust and historical trauma. Each participant expressed similar points of view when asked the interview question: *What do you know about the history of medical racism in the US?*

When asked what she knows about the history of medical racism in the United States, Participant A stated that she is aware of the history of medical racism. When asked to elaborate, she listed the Tuskegee Experiment, HeLa cells, and Serena Williams's near-death birthing experience as examples of medical racism.

Similarly, Participant B listed the Tuskegee Experiment and HeLa cells as well. They also discussed how racism fueled Planned Parenthood and the eugenics movement.

Like the other participants, Participant C also listed HeLa cells as one example of medical racism. Additionally, she discussed health disparities and Black maternal death rates. She talked about the idea that Black people have tougher skin and are resistant to pain. Each participant expressed similar points of view when asked the interview question: *Do you believe that medical racism still exists within the US healthcare system? Why or why not?*

Participant A stated that she does believe that medical racism still exists in the United States. She explained that some physicians still have biases whether or not they realize it. Because of these biases, assumptions are made and the trajectory of care is impacted which can

“lead to people not receiving the amount of care they need, deserve, and require”. Participant A also noted that medical racism can look like “not believing symptoms and not taking symptoms seriously.” She also stated that this dismissal can impact a patient’s level of trust and their relationship with their doctor.

When asked if they believe medical racism still exists, Participant B stated “Is a pig pork?” to emphasize that they do believe that medical racism still exists in the United States. They explained that medical racism is not a novel issue, but recently people have been becoming more aware of the issue. They listed the internet as a resource that has been used to distribute information about medical racism as well as bring awareness to it. They believe that though medical racism is not as severe as it once was, the United States still has a long way to go to eradicate it.

Likewise, Participant C stated that she does believe that medical racism still exists. She further explained that there is a lack of understanding of Black pain and experiences. She believes that racism in general exists and is still a major problem in the United States.

Each participant expressed similar points of view when asked the interview question:  
*How do you feel your race affects your medical experiences?*

Participant A said that she feels that her medical experiences depend on the type of doctor she visits. She has a good rapport with her primary care physician so she tends to have good experiences. She does not know if her experiences would be the same with other doctors. Though she is happy with her care, she did note that having a doctor that looks like her, Black and female, is not as convenient. She stated that she has to travel further for a doctor that fits her preference.

On the other hand, Participant B stated that they believe that their race impacts their

medical experiences in many ways. They feel that it is sad that people do not recognize medical racism as a real problem when there is existing research and examples. They hope that people eventually wake up and see medical racism as a public health issue and recognize the importance of cultural sensitivity in healthcare.

Similarly, when asked how her race impacts her medical experiences, Participant C stated that it causes her to be more apprehensive when navigating the healthcare system. She feels pressure to remain healthy so that she does not have to see a doctor and potentially have experiences with medical racism.

*Research Question 3: How have the views of their families affected young Black adults' current levels of medical mistrust?*

This research question was also answered using the qualitative interviews conducted with three of the survey participants. Themes related to the history of medical racism in the United States and its effects on the attitudes towards the healthcare of young Black adults included: medical mistrust, racial socialization, and intergenerational transmission. Each participant expressed similar points of view when asked the interview question: *Where did you learn information about the history of medical racism in the US?*

When asked where she learned information about the history of medical racism, Participant A said that she mainly learned about medical racism from her family and at school. She cited her mother's experience while having breast cancer as an example of how she learned about medical racism. Participant A stated that her mother expressed that her doctor was very dismissive towards her regarding her symptoms. Participant A's mother taught her to "reiterate your symptoms to bring attention to them and make sure your voice is heard."

When asked where they learned information about the history of medical racism,

Participant B said that they mainly learned about medical racism from their parents. Their parents did their own research on the topic and passed their knowledge down to them. Another more recent source of information on medical racism for them has been their medical social work class. This class did not provide a comprehensive overview of the history, but it did briefly cover the impact of medical racism on the healthcare system.

Participant C said that she mainly learned about medical racism from her mom who has worked in healthcare since the 80s. Participant C also noted that she has learned about medical racism from social media.

Each participant expressed varying points of view when asked the interview question:  
*What type of relationship do your parents have with the US healthcare system?*

Participant A stated that her parents have a good relationship with the United States healthcare system.

Participant B stated that their parents are very skeptical of the healthcare system in the United States. Though they are skeptical, they realize the importance of healthcare utilization especially as they grow older.

Participant C stated that her parents have always gone out their way to find doctors who are people of color. She also noted that her grandmother is distrustful of the healthcare system but because of the status of her health she has to see doctors and listen to their advice.

Each participant expressed varying points of view when asked the interview question:  
*What conversations have your parents/guardians had with you regarding the healthcare system?*

When asked what conversations her family had with her regarding the healthcare system, Participant A said that most of her conversations regarding the health care system were centered around advice. Her family would talk to her about what services she needed and how to schedule

appointments.

When asked what conversations their family had with them regarding the healthcare system, Participant B said that their parents are “pro-Black” and taught them a lot about Black history and medical racism in the United States. Participant B’s parents provided them with several warnings including that “the system is not for Black people.” They also told her to document every experience and to be sure to get an itemized bill for everything. Participant B learned to be hyper-aware and cautious, but also the importance of healthcare utilization.

When asked what conversations her family had with her regarding the healthcare system, Participant C explained that she and her parents had not had any formal conversations regarding the healthcare system in the United States. She stated that she has multiple family members who work in the healthcare field and she has been told about some of the things that go on behind the scenes. Her mother has shared her work experiences and given advice on how to navigate the healthcare system. Her mother also stressed the fact that not every healthcare professional will have her best interest at heart.

*Research Question 4: How does medical mistrust impact healthcare utilization?*

The quantitative data from the survey responses was used to answer this research question. Prior to examining the relationship between medical mistrust and healthcare utilization, data for both variables were inspected for normality. Measures of central tendency, skewness coefficients, histograms, and normal Q-Q plots ensured that both medical mistrust and the healthcare utilization measures were normally distributed. The null hypothesis is there is no statistically significant relationship between medical mistrust and healthcare utilization. The alternative hypothesis is there is a statistically negative relationship between medical mistrust and impact healthcare utilization. This means the higher an individual’s level of mistrust, the less

they utilize healthcare. A Spearman's  $\rho$  test was used because the sample size, 11, was too small and did not meet the assumptions of the Pearson's test.

In order to determine the relationship between medical mistrust and healthcare utilization, a one-tailed test was run because the researcher hypothesized with higher levels of medical mistrust there would be lower levels of healthcare utilization. For this test, the independent variable was level of medical mistrust and the dependent variables were individual healthcare utilization variables pulled from Section C: Healthcare Utilization of the *Medical Mistrust Survey* (2003). These variables included: delayed treatment, not seeking treatment, not getting prescriptions filled, not returning for follow-ups, and not following the doctor's orders.

The results of the Spearman's  $\rho$  test show a negative, but insignificant relationship ( $\rho = -0.287$ ,  $p < 0.05$ ) between medical mistrust level and delayed treatment. In other words, those who have higher levels of medical mistrust do tend to delay treatment, but not at a statistically significant level.

The results of the Spearman's  $\rho$  test show a negative, but insignificant relationship ( $\rho = -0.264$ ,  $p < 0.05$ ) between medical mistrust level and not seeking treatment. In other words, those who have higher levels of medical mistrust tend to not seek medical treatment, but not at a statistically significant level.

The results of the Spearman's  $\rho$  test show a negative, but insignificant relationship ( $\rho = -0.165$ ,  $p < 0.05$ ) between medical mistrust level and not getting prescriptions filled. In other words, those who have higher levels of medical mistrust tend to not get their prescriptions filled, but not at a statistically significant level.

The results of the Spearman's  $\rho$  test show a negative, but insignificant relationship ( $\rho = -0.403$ ,  $p < 0.05$ ) between medical mistrust level and not coming back for a follow-up



appointment. In other words, those who have higher levels of medical mistrust tend to not return for follow up appointments, but not at a statistically significant level.

The results of the Spearman's  $\rho$  test show a positive, but insignificant relationship ( $\rho = 0.186$ ,  $p < 0.05$ ) between medical mistrust level and not following the doctor's orders. In other words, those who have higher levels of medical mistrust tend not to follow the doctor's orders, but not at a statistically significant level.

Through these tests it was found that medical mistrust does not impact healthcare utilization at a statistically significant level. The null hypothesis is accepted.

[See Table 1]

Table 1. Medical Mistrust and Healthcare Utilization

|                     |                 | Delayed<br>Treatmen<br>t | No<br>Treatment | No<br>Prescription | No Follow-<br>Up | No Doctor's<br>Orders |
|---------------------|-----------------|--------------------------|-----------------|--------------------|------------------|-----------------------|
| Medical<br>Mistrust | Correlation     | -.287                    | -.264           | -.165              | -.403            | .186                  |
|                     | Coefficient     |                          |                 |                    |                  |                       |
|                     | Sig. (1-tailed) | .196                     | .216            | .314               | .124             | .316                  |
|                     | N               | 11                       | 11              | 11                 | 10               | 9                     |

This research question was also answered using the qualitative interviews conducted with three of the survey participants. Themes related to medical mistrust and individual healthcare utilization included: medical mistrust, healthcare accessibility, and perseverance. Though each interview participant stated that they do not allow their level of mistrust to keep them from going to the doctor, their doctor preference and accessibility of doctors is one way medical mistrust impacts healthcare utilization. Each participant expressed similar points of view when asked the interview question: *If you could choose, would you prefer to be treated by a doctor of your own race or ethnic group, another race or ethnic group, or do you have no preference? Why?*

Participant A stated that she prefers seeing doctors of her own race. Participant A also said that she is very picky about her doctors and she selected her current doctor on her own after

doing research. She prefers this because she believes that Black doctors can better relate to her and her issues. She also believes that she has a lesser chance of her voice not being heard.

Participant B stated that they have had the best medical experience with Black woman doctors so that is what they prefer. They explained that Black woman doctors provide a level of cultural understanding that was missing with previous providers. Participant B and their current doctor developed an immediate rapport and they felt comfortable.

Participant C states that she prefers a doctor of her own race. She feels as though they are more willing to listen to her concerns. She also stated that, from her experience, their client base tends to be Black as well, so they are better equipped to work with Black clients like herself. She believes that Black doctors tend to have more cultural awareness and are able to diagnose her easier because they understand her.

Each participant expressed similar points of view when asked the interview question: *Are doctors that fit your preference easily accessible?*

Participant A states that she feels like physicians that fit her preference tend to be further in distance and less accessible.

Participant B's current doctor is not easily accessible, and they have to travel 20 minutes, without having a vehicle of their own for a doctor that fits their preference.

Participant C stated that doctors that fit her preference are not easily accessible. Her current doctor is located in the city her university is located and she can only visit in person while she is there during the semester. Her doctor also tends to be booked for 1 to 2 months out so she tends to have to wait for an available appointment.

*Research Question 5: How do direct experiences with medical racism impact young Black adult healthcare utilization?*

The quantitative data from the survey responses was used to answer this research question. Prior to examining the relationship between direct experiences with medical racism and healthcare utilization, data for both variables were inspected for normality. Measures of central tendency, skewness coefficients, histograms, and normal Q-Q plots ensured that both medical mistrust and the healthcare utilization measures were normally distributed. The null hypothesis is there is no statistically significant relationship between direct experiences with medical racism and healthcare utilization. The alternative hypothesis is there is a statistically significant negative relationship between direct experiences with medical racism and healthcare utilization. This means that if an individual personally experienced medical racism, they are less likely to utilize healthcare. A Spearman's *rho* test was used because the sample size, 11, was too small and did not meet the assumptions of the Pearson's test. The results of each variable were as follows:

In order to determine the relationship between direct experiences with medical racism and healthcare utilization, a one-tailed test was run because the researcher hypothesized that individuals who had personal experiences with medical racism would have lower levels of healthcare utilization. For this test, the independent variable was a personal experience with medical racism and the dependent variables were healthcare utilization variables pulled from Section C: Healthcare Utilization of the *Medical Mistrust Survey* (2003). These variables included: delayed treatment, not seeking treatment, not getting prescriptions filled, not returning for follow ups, and not following the doctor's orders.

The results of the Spearman's *rho* test show a negative, but insignificant relationship ( $\rho = -0.287$ ,  $p < 0.05$ ) between a personal experience of medical racism and delayed treatment. In other words, those who have personally experienced medical racism do tend to delay treatment, but not at a statistically significant level.

The results of the Spearman's *rho* test show a negative, but insignificant relationship ( $\rho = -0.194$ ,  $p < 0.05$ ) between a personal experience of medical racism and not seeking treatment. In other words, those who have personally experienced medical racism tend to not seek treatment, but not at a statistically significant level.

The results of the Spearman's *rho* test show a positive, but insignificant relationship ( $\rho = 0.194$ ,  $p < 0.05$ ) between a personal experience with medical racism and not filling prescriptions. In other words, those who have personally experienced medical racism do get their prescriptions filled, but not at a statistically significant level.

The results of the Spearman's *rho* test show a negative, but insignificant relationship ( $\rho = -0.272$ ,  $p < 0.05$ ) between a personal experience with medical racism and not coming back for a follow-up appointment. In other words, those who have personally experienced medical racism tend to not return for follow up appointments, but not at a statistically significant level.

The results of the Spearman's *rho* test show a positive, but insignificant relationship ( $\rho = 0.5$ ,  $p < 0.05$ ) between a personal experience with medical racism and not following the doctor's orders. In other words, those who have personally experienced medical racism tend to follow the doctor's orders, but not at a statistically significant level.

Through these tests it was found that direct experiences with medical racism do not impact healthcare utilization at a statistically significant level. The null hypothesis is accepted.  
[See Table 2]

Table 2. Personal Experience with Medical Racism and Healthcare Utilization

|                        |                                | Delayed<br>Treatmen<br>t | No<br>Treatment | No<br>Prescription | No<br>Follow-<br>Up | No<br>Doctor's<br>Orders |
|------------------------|--------------------------------|--------------------------|-----------------|--------------------|---------------------|--------------------------|
| Personal<br>Experience | Correlation                    | -.280                    | -.194           | .194               | -.272               | .500                     |
|                        | Coefficient<br>Sig. (1-tailed) | .202                     | .284            | .284               | .223                | .085                     |

|   |    |    |    |    |   |
|---|----|----|----|----|---|
| N | 11 | 11 | 11 | 10 | 9 |
|---|----|----|----|----|---|

This research question was also answered using the qualitative interviews conducted with three of the survey participants. Themes related to direct experiences with medical racism and individual healthcare utilization included: racial trauma, medical mistrust, and perseverance. Each participant shared their experiences when asked the interview question: *Have you personally experienced what you perceived as medical racism? Describe the incident.* Participants were also asked: *How did/does it affect you?*

Participant A reported that she had not personally experienced medical racism and she did not have a story to share in response to this interview question.

Participant B reported that they have had a personal experience with medical racism. They told the story about how they went to the hospital because they were having an irregularly long menstrual cycle, three months. The health providers asked about their sexual activity and when they told the providers that they had not had sex in the past 6 months they were not believed. The doctor insisted that Participant B begin taking birth control, and they declined based on their own prior knowledge and the fact that the doctor provided no real diagnosis. It is also important to note that Participant B identifies as lesbian, but the health care providers did not ask or take their sexual orientation into consideration when making their suggestion. After being told there was nothing else they could do for them, Participant B left the hospital and ended up experiencing another 5 months of bleeding. They eventually took their health into their own hands, and after changing their diet and incorporating exercise into their life the bleeding ceased. Though Participant B left the hospital after receiving no tests, diagnosis, or help, they were later sent a bill for \$5,000 that included services that they did not receive. After sharing their story, Participant B was asked how the situation impacted them. They said that the experience impacted them greatly because the constant bleeding caused them to experience

fatigue. This led to their academics being negatively impacted because they could not attend class at times, but did not have a doctor's excuse to provide because there was no diagnosis. Though it took some time to recover from this incident, Participant B has now chosen to not allow their experience with medical racism to keep them from seeking help when they need it.

Participant C has also had a personal experience with medical racism. When she was about 6-years-old she was experiencing what she later found out was atopic dermatitis. Prior to her diagnosis, she was constantly having blood drawn and tests run to determine what the problem was. She stated that she feels like that was not good for a child so young. She also felt that her and her parents' voices were not being heard in that situation. Eventually, her parents took her to see a Black doctor who was quickly able to identify the problem and provide her with a diagnosis. This instance solidified her and her parents' preference for Black doctors moving forward. Though she recognizes the importance of healthcare utilization and will go to the doctor if she has to, Participant C's previous experience causes her to be stressed and hyper-focused on staying healthy to avoid having to go to the doctor.

*Research Question 6: How do indirect experiences with medical racism impact young Black adult healthcare utilization?*

The quantitative data from the survey responses was used to answer this research question. Prior to examining the relationship between indirect experiences with medical racism and healthcare utilization, data for both variables were inspected for normality. Measures of central tendency, skewness coefficients, histograms, and normal Q-Q plots ensured that both medical mistrust and the healthcare utilization measures were normally distributed. The null hypothesis is there is no statistically significant relationship between indirect experiences with medical racism and healthcare utilization. The alternative hypothesis is there is a statistically

negative relationship between indirect experiences with medical racism and impact healthcare utilization. This means the higher an individual's level of mistrust, the less they utilize healthcare. A Spearman's  $\rho$  test was used because the sample size, 11, was too small and did not meet the assumptions of the Pearson's test. The results of each variable were as follows:

In order to determine the relationship between family experiences with medical racism and healthcare utilization, a one-tailed test was run because the researcher predicted that those who have relatives who have experienced medical racism would have lower levels of healthcare utilization. For this test, the independent variable was family experience with medical racism and the dependent variables were healthcare utilization variables pulled from Section C: Healthcare Utilization of the *Medical Mistrust Survey* (2003). These variables included: delayed treatment, not seeking treatment, not getting prescriptions filled, not returning for follow-ups, and not following the doctor's orders.

The results of the Spearman's  $\rho$  test show a strong negative significant relationship ( $\rho = -0.838$ ,  $p < 0.05$ ) between relative experience of medical racism and delayed treatment. In other words, those who have relatives who have experienced medical racism do tend to delay treatment at a statistically significant level.

The results of the Spearman's  $\rho$  test show a negative, but insignificant relationship ( $\rho = -0.385$ ,  $p < 0.05$ ) between family experience of medical racism and not seeking treatment. In other words, those who have relatives who have experienced medical racism do tend to not seek treatment, but not at a significant level.

The results of the Spearman's  $\rho$  test show a negative, but insignificant relationship ( $\rho = -0.039$ ,  $p < 0.05$ ) between family experience of medical racism and not filling prescriptions. In other words, those who have relatives who have experienced medical racism do

tend to not fill their prescriptions, but not at a significant level.

The results of the Spearman's  $\rho$  test show a negative significant relationship ( $\rho = -0.583$ ,  $p < 0.05$ ) between family experience of medical racism and not coming back for a follow-up appointment. In other words, those who have relatives who have experienced medical racism do tend to not return for follow up appointments, at a statistically significant level.

The results of the Spearman's  $\rho$  test show a negative, but insignificant relationship ( $\rho = -0.316$ ,  $p < 0.05$ ) between family experience of medical racism and not following the doctor's orders. In other words, those who have relatives who have experienced medical racism do tend to not follow the doctor's orders, but not at a statistically significant level.

Through these tests it was found that family experiences with medical racism do impact healthcare utilization at a negative statistically significant level when it comes to delays in treatment and returning for follow-up appointments. The null hypothesis is rejected for those variables. [See Table 3]

Table 3: Relative Experience with Medical Racism and Healthcare Utilization

|                      |                 | Delayed<br>Treatmen<br>t | No<br>Treatment | No<br>Prescription | No<br>Follow-<br>Up | No<br>Doctor's<br>Orders |
|----------------------|-----------------|--------------------------|-----------------|--------------------|---------------------|--------------------------|
| Family<br>Experience | Correlation     | -.838**                  | -.386           | -.039              | -.583*              | -.316                    |
|                      | Coefficient     |                          |                 |                    |                     |                          |
|                      | Sig. (1-tailed) | <.001                    | .121            | .455               | .038                | .204                     |
|                      | N               | 11                       | 11              | 11                 | 10                  | 9                        |

In order to determine the relationship between friends' experiences with medical racism and healthcare utilization, a one-tailed test was run because the researcher predicted that those who have friends who have experienced medical racism would have lower levels of healthcare utilization. For this test, the independent variable was friend experience with medical racism and the dependent variables were healthcare utilization variables pulled from Section C: Healthcare Utilization of the *Medical Mistrust Survey* (2003). These variables included: delayed treatment,



not seeking treatment, not getting prescriptions filled, not returning for follow ups, and not following the doctor's orders.

The results of the Spearman's  $\rho$  test show a positive, but insignificant relationship ( $\rho = 0.324$ ,  $p < 0.05$ ) between friends' experience of medical racism and delayed treatment. In other words, those who have friends who have experienced medical racism tend to delay treatment, but not at a statistically significant level.

The results of the Spearman's  $\rho$  test show a negative, but insignificant relationship ( $\rho = -0.149$ ,  $p < 0.05$ ) between friends' experience of medical racism and delayed treatment. In other words, those who have friends who have experienced medical racism do tend to not seek treatment, but not at a statistically significant level.

The results of the Spearman's  $\rho$  test show a positive significant relationship ( $\rho = 0.559$ ,  $p < 0.05$ ) between friend experience of medical racism and filling prescriptions. In other words, those who have friends who have experienced medical racism tend to get their prescriptions filled, but not at a statistically significant level.

The results of the Spearman's  $\rho$  test show a positive, but insignificant relationship ( $\rho = 0.408$ ,  $p < 0.05$ ) between friends' experience of medical racism and not coming back for a follow up appointment. In other words, those who have friends who have experienced medical racism tend to return for follow-up appointments, but not at a statistically significant level.

The results of the Spearman's  $\rho$  test show a positive, but insignificant relationship ( $\rho = 0.316$ ,  $p < 0.05$ ) between friends' experience of medical racism and not following the doctor's orders. In other words, those who have friends who have experienced medical racism tend to follow the doctor's orders, but not at a statistically significant level.

Through these tests it was found that friends' experiences with medical racism do impact

healthcare utilization at a statistically significant level when it comes to filling prescriptions. The null hypothesis is accepted. [See Table 4]

Table 4. Friends' Experience with Medical Racism and Healthcare Utilization

|                        |                 | Delayed<br>Treatmen<br>t | No<br>Treatment | No<br>Prescription | No<br>Follow-<br>Up | No<br>Doctor's<br>Orders |
|------------------------|-----------------|--------------------------|-----------------|--------------------|---------------------|--------------------------|
| Friends'<br>Experience | Correlation     | .324                     | -.149           | .559*              | -.408               | .316                     |
|                        | Coefficient     |                          |                 |                    |                     |                          |
|                        | Sig. (1-tailed) | .166                     | .331            | .037               | .121                | .204                     |
|                        | N               | 11                       | 11              | 11                 | 10                  | 9                        |

This research question was also answered using the qualitative interviews conducted with three of the survey participants. Themes related to indirect experiences with medical racism and individual healthcare utilization included: medical mistrust, intergenerational transmission, and peer transmission. Each participant shared their experiences when asked the interview question: *Has anyone close to you, including family and friends, experienced what they perceived as medical racism? Describe the incident.* Participants were also asked: *How did you feel when you heard about this?* These are the responses the participants gave related to their utilization of healthcare following the incidents:

When asked about the experiences of those close to her with medical racism and how it impacted her, Participant A described a situation in which her sister experienced medical racism. At the time, her sister's doctor told her that her body mass index (BMI) was too high. This caused her sister to feel pressured to change her lifestyle and diet in an effort to achieve a "normal weight." Her sister also felt scorned because of this experience. Though Participant A reported that she feels comfortable when going to the doctor, she also reported feeling on guard when navigating the healthcare system. She said that this experience made her picky about what doctor she visits. Also, this experience causes her to be very proactive about her health and when she has to go to the doctor she tends to ensure she is over-prepared for her visits.

Participant B shared an experience that a friend had with medical racism. They stated that their friend has a very serious diagnosis of endometriosis that tends to cause her a lot of pain. One day she was experiencing a bad attack and decided to visit the student health center. During this visit, the receptionist was not trying to help her because she did not have an appointment. When her friend tried to advocate for herself and request to be seen she was then told to go to the emergency room instead. As she continued to advocate for herself through the pain she was in, she was called rude and was still turned away. Participant B noted that their friend has a “strong tone” and tends to be perceived as “rude” or “aggressive” often when she is not trying to be. Participant B also stated that they have heard numerous other stories of people close to them experiencing medical racism. They also stated that they know of individuals who will not visit certain hospitals in dire situations out of fear of how they will be treated because of their race. Participant B does not visit the student health center because of the experiences of those close to them as well as their personal experiences. Participant B would rather travel 20 minutes from campus to visit a doctor that fits their preference.

Participant C stated that though her parents provided many warnings, she was unsure if they had personally experienced medical racism. Participant C stated that her grandmother would often share her experiences. Participant C’s grandmother shared stories about doctors being mean and dismissive towards her. Though no one close to Participant C had been harmed by medical racism, the experiences of those close to her contribute to her constant effort to stay healthy to avoid having to see a doctor.

*Research Question 7: How do direct experiences with medical racism impact medical mistrust?*

Prior to examining the relationship between direct experiences with medical racism and medical mistrust, data for both variables were inspected for normality. Measures of central

tendency, skewness coefficients, histograms, and normal Q-Q plots ensured that both medical mistrust and the healthcare utilization measures were normally distributed. The null hypothesis is there is no statistically significant relationship between direct experiences with medical racism and medical mistrust. The alternative hypothesis is there is a statistically positive relationship between direct experiences with medical racism and medical mistrust. This means individuals who have personally experienced medical racism will have a higher level of medical mistrust. A Spearman's *rho* test was used because the sample size, 11, was too small and did not meet the assumptions of the Pearson's test. The results were as follows:

In order to determine the relationship between direct experiences with medical racism and medical mistrust, a one-tailed test was run because the researcher predicted those who have personally experienced medical racism would have higher levels of medical mistrust. For this test, the independent variable was personal experience of medical racism and the dependent variable was medical mistrust level.

The results of the Spearman's *rho* test show a positive, but insignificant relationship ( $rho = 0.051$ ,  $p < 0.05$ ) between personal experience of medical racism and level of medical mistrust. In other words, those who have personally experienced medical racism have higher levels of mistrust, but not at a statistically significant level. The null hypothesis is accepted. [See Table 5]

Table 5. Experiences with Medical Racism & Medical Mistrust

|                  |                         | Personal Experience | Family Experience | Friend's Experience |
|------------------|-------------------------|---------------------|-------------------|---------------------|
| Medical Mistrust | Correlation Coefficient | .051                | .275              | .089                |
|                  | Sig. (1-Tailed)         | .441                | .206              | .398                |
|                  | N                       | 11                  | 11                | 11                  |

This research question was also answered using the qualitative interviews conducted with three of the survey participants. Themes related to direct experiences with medical racism and

medical mistrust included: medical mistrust, racial trauma, and perseverance. Each participant shared their experiences when asked the interview question: *How did/does it (personal experience with medical racism) affect you?* These are the responses the participants gave related to their feelings following the incidents:

Participant A previously reported that she had not personally experienced medical racism and she did not have a response to this interview question.

Following their personal experience with medical racism, the doctors failing to provide a diagnosis then billing her for services she did not receive, Participant B blamed themselves for the situation. They believed that the healthcare providers did not take them seriously because of how calm they were about their condition. Participant B noted that they feel like their being uninsured impacted the experience as well because they believe that healthcare providers do not treat uninsured patients equally. Participant B also felt that they should have been more prepared when they went in for the visit and hates that they feel that pressure. Eventually Participant B was able to change the narrative and realize that this negative medical experience does not define them and does not need to keep them from seeking help when needed. Now Participant B tries to remember the good in healthcare though they feel like it is challenging at times.

Since her experience with medical racism, undergoing numerous tests as a young child until a Black doctor finally provided a diagnosis, Participant C reported that visiting the doctor causes her to experience stress. Her experience also made her prefer to only visit Black doctors out of fear of not being heard and being dismissed again. Overall, Participant C stated that she is typically apprehensive when it comes to the healthcare system in the United States.

*Research Question 8: How do indirect experiences with medical racism impact medical mistrust?*

Prior to examining the relationship between indirect experiences with medical racism and medical mistrust, data for both variables were inspected for normality. Measures of central tendency, skewness coefficients, histograms, and normal Q-Q plots ensured that both medical mistrust and the healthcare utilization measures were normally distributed. The null hypothesis is there is no statistically significant relationship between indirect experience with medical racism and medical mistrust. The alternative hypothesis is there is a statistically significant relationship between indirect experience with medical racism and medical mistrust. This means that individuals who have family or friends who have experienced medical racism will have higher levels of medical mistrust. A Spearman's *rho* test was used because the sample size, 11, was too small and did not meet the assumptions of the Pearson's test. The results were as follows:

In order to determine the relationship between relative experiences with medical racism and medical mistrust, a one-tailed test was run because the researcher predicted that those who have relatives who have experienced medical racism would have higher levels of medical mistrust. For this test, the independent variable was relative experience with medical racism and the dependent variable was medical mistrust level. The results of the Spearman's *rho* test show a positive, but insignificant relationship ( $rho = 0.275$ ,  $p < 0.05$ ) between relative experience of medical racism and level of medical mistrust. In other words, those who have relatives who have experienced medical racism have higher levels of mistrust, but not at a statistically significant level. The null hypothesis is accepted. [See Table 5]

In order to determine the relationship between friends' experiences with medical racism and medical mistrust, a one-tailed test was run because the researcher predicted that those who have relatives who have experienced medical racism would have higher levels of medical mistrust. For this test, the independent variable was friends' experience with medical racism and

the dependent variable was medical mistrust. The results of the Spearman's *rho* test show a positive, but insignificant relationship ( $\rho = 0.089$ ,  $p < 0.05$ ) between friends' experience of medical racism and level of medical mistrust. In other words, those who have friends who have experienced medical racism have higher levels of mistrust, but not at a statistically significant level. The null hypothesis is accepted. [See Table 5]

This research question was also answered using the qualitative interviews conducted with three of the survey participants. Themes related to indirect experiences with medical racism and medical mistrust included: medical mistrust and transmission. Each participant shared their experiences when asked the interview question: *How did you feel when you heard about this (family or friends experiences with medical racism)?* These are the responses the participants gave related to their feelings following the incidents:

When asked how her sister's experience with medical racism made her feel about the healthcare system in the United States, Participant A said that at the time it made her feel like her sister was abnormal when there was really no reason for concern. Now she is shocked that assumptions were made about her sister and annoyed that she had to go through that experience. This experience also taught her the importance of knowing how to advocate for herself in situations like that.

When asked about how their friend's experience made them feel about the healthcare system in the United States, Participant B said that the situation and their own experience make it hard to trust doctors and healthcare professionals. They know that they have to prioritize their health, but they stated that these situations make it hard to believe that there are good doctors and healthcare professionals out there.

When asked how her family's experiences made her feel about the healthcare system in

the United States, Participant C said whenever she hears stories they add to her stress. She worries about truly being heard and cared for when visiting doctors who are not Black.

### *Quantitative Findings*

Through the eleven survey responses it was found that medical mistrust does not impact healthcare utilization at a statistically significant level. It was also found that direct experiences with medical racism do not impact healthcare utilization. Results show that family experiences with medical racism do impact healthcare utilization at a statistically significant level when it comes to delays in treatment and returning for follow-up appointments. It was also found that friends' experiences with medical racism affect healthcare utilization at a statistically significant level when it comes to filling prescriptions. Results show that those who have personally experienced medical racism have higher levels of medical mistrust, but not at a statistically significant level. Those who have family members who have experienced medical racism have higher levels of medical mistrust, but not at a statistically significant level. Those who have friends who have experienced medical racism have higher levels of medical mistrust, but not at a statistically significant level.

Table 6. Summary of Quantitative Findings

|                     |                     | Delayed<br>Treatment | No<br>Treatment | No<br>Prescription | No Follow-<br>Up | No Doctor's<br>Orders |
|---------------------|---------------------|----------------------|-----------------|--------------------|------------------|-----------------------|
| Medical<br>Mistrust | Correlation         | -.287                | -.264           | -.165              | -.403            | .186                  |
|                     | Coefficient         |                      |                 |                    |                  |                       |
|                     | Sig. (1-<br>tailed) | .196                 | .216            | .314               | .124             | .316                  |
|                     | N                   | 11                   | 11              | 11                 | 10               | 9                     |



(Table 6  
contd.)

|                        |                         | Delayed<br>Treatment | No<br>Treatment        | No<br>Prescription   | No<br>Follow-<br>Up    | No<br>Doctor's<br>Orders |
|------------------------|-------------------------|----------------------|------------------------|----------------------|------------------------|--------------------------|
| Personal<br>Experience | Correlation             | -.280                | -.194                  | .194                 | -.272                  | .500                     |
|                        | Coefficient             |                      |                        |                      |                        |                          |
|                        | Sig. (1-tailed)         | .202                 | .284                   | .284                 | .223                   | .085                     |
|                        | N                       | 11                   | 11                     | 11                   | 10                     | 9                        |
|                        |                         |                      |                        |                      |                        |                          |
|                        |                         | Delayed<br>Treatment | No<br>Treatment        | No<br>Prescription   | No<br>Follow-<br>Up    | No<br>Doctor's<br>Orders |
| Family<br>Experience   | Correlation             | -.838**              | -.386                  | -.039                | -.583*                 | -.316                    |
|                        | Coefficient             |                      |                        |                      |                        |                          |
|                        | Sig. (1-tailed)         | <.001                | .121                   | .455                 | .038                   | .204                     |
|                        | N                       | 11                   | 11                     | 11                   | 10                     | 9                        |
|                        |                         |                      |                        |                      |                        |                          |
|                        |                         | Delayed<br>Treatment | No<br>Treatment        | No<br>Prescription   | No<br>Follow-<br>Up    | No<br>Doctor's<br>Orders |
| Friends'<br>Experience | Correlation             | .324                 | -.149                  | .559*                | -.408                  | .316                     |
|                        | Coefficient             |                      |                        |                      |                        |                          |
|                        | Sig. (1-tailed)         | .166                 | .331                   | .037                 | .121                   | .204                     |
|                        | N                       | 11                   | 11                     | 11                   | 10                     | 9                        |
|                        |                         |                      |                        |                      |                        |                          |
|                        |                         |                      | Personal<br>Experience | Family<br>Experience | Friend's<br>Experience |                          |
| Medical Mistrust       | Correlation Coefficient |                      | .051                   | .275                 | .089                   |                          |
|                        | Sig. (1-Tailed)         |                      | .441                   | .206                 | .398                   |                          |
|                        | N                       |                      | 11                     | 11                   | 11                     |                          |

### *Qualitative Findings*

Through interviews with the three survey participants it has been found that there is a certain level of mistrust among young Black adults in the United States. It was also found that personal experiences with medical racism as well as the experiences of family and friends add to

their current levels of mistrust. Interview participants expressed that though they are aware of these experiences and do not trust the healthcare system, they do not allow their mistrust to impact their healthcare utilization because they understand the importance of proper healthcare utilization.

## **Chapter 5. Discussion**

The purpose of this exploratory study was to identify the ways in which the United States' history of medical racism impacts contemporary Black young adults and their attitudes toward the healthcare system as well as healthcare utilization. This study was conducted through the lens of three theories: critical race theory, historical trauma theory, and family systems theory. This study also explored the concept of the intergenerational transmission of trauma focusing on medical racial trauma and medical mistrust in Black families.

### *Limitations*

There were two limitations of this study. One the limitations was the sample size. Convenience sampling was used to recruit participants for this study. There were a total of 18 survey responses collected. Once the data was cleaned and coded, it was found that 11 out of those 18 responses were not completed and able to be used in the study. Of the 11 participants who completed the survey, 3 volunteered to take part in the interview portion of the study. Another study limitation was the participant demographics. All of the study participants were students currently enrolled at a large public university located in a large southern city. Due to these limitations, the results of this study cannot be generalized to the population of young Black adults in the United States. Though this study is not representative the of overall population, it can be used as a starting point for more research focused on the impact of the history of medical racism on young Black adults and the intergenerational transmission of medical racial trauma in Black families.

### *Implications*

Despite these limitations, these results of this exploratory study suggest several theoretical implications. First, the data collected in this study can be supported by multiple tenets

of critical race theory. One of the tenets that supports the data is the second tenet of critical race theory which is racism is normal and a common experience for people of color (Delgado & Stefancic, 2017). The fourth tenet of critical racism differential racialization, also supports the data. This is the attribution of negative stereotypes to racial groups based on the interests of White people (Delgado & Stefancic, 2017). While telling the story of their friend's experience, Participant B stated that their friend has a "strong tone" and tends to be perceived as "rude" or "aggressive" often when she is not trying to be. This is an example of the "Angry Black Woman" stereotype that has historically be ascribed to Black women (Steele, 2016; Toms-Anthony, 2018). The final tenet of critical race theory that supports the data this study is intersectionality, the idea that "no person has a single, easily stated, unitary identity" (Delgado & Stefancic, 2017, p. 9). Participant B, who identifies as gender non-binary and lesbian was told by medical professionals that they should take birth control to solve their issue of vaginal bleeding. Though Participant B did feel that their race played a role in this experience, they also noted that their sexual orientation should have been considered when the medical professionals made this rushed suggestion.

The results of this study also can also be supported by family systems theory and the idea of the intergenerational transmission of trauma. The quantitative data suggests that family experiences with medical racism do impact healthcare utilization at a statistically significant level when it comes to delays in treatment and returning for follow-up appointments. It was also discovered that those who have family members who have experienced medical racism have higher levels of medical mistrust, but not at a statistically significant level. The interview responses suggest that the family is a primary source of information. Two out of three of the interview participants included examples of warnings their families gave them regarding their

safety and well-being when navigating the healthcare system. All three of the interview participants reported feeling a certain level of mistrust towards the healthcare system in the United States. Based on the both the quantitative and qualitative data collected, the ideas that members of a family are interdependent and trauma can be transmitted across generations can be applied to the results of this exploratory story (Fitzgerald et al., 2020).

The results of this study can also be supported by historical trauma theory. As previously stated, historical trauma is caused by a cumulative traumatic experience that has a lasting impact across generations which leads to a collective group experience (Brave Heart, 2003). What is displayed in this study could be interpreted as the third and final phase of historical trauma. The third and final phase involves later generations being negatively impacted by the trauma their ancestors endured. Based on the data collected, this theory could be applied to both the quantitative and qualitative results of this exploratory study. The quantitative results show the impact, though not statistically significant, of the history of medical racism in the United States on young Black adults. These results align with the qualitative interview responses. All three of the interview participants cited their knowledge of medical racism in the United States as part of their reasoning behind their level of mistrust and healthcare utilization practices.

There are also several practical implications that can be associated with the results of this study. First, the results of this study draw attention to the current disparities within the healthcare system in the United States. For example, interview participants saying their doctors are not easily accessible. Another example Participant C noting the lack of cultural awareness and understanding that is often perpetuated by doctors who are not of color. Also, the results of this study can be used to support the need for therapy and interventions for families who have been impacted by racial and historical trauma. The end goal would be to help these families heal and

to eventually eradicate the intergenerational transmission of trauma.

#### *Directions for Future Research*

Much work remains to be done before a full understanding of the extent of the impact of medical racism in the United States is established. In terms of future research, it would be useful to extend the current findings by examining the intergenerational transmission of medical racial trauma and medical mistrust in Black families. The connections between this phenomenon and critical race theory, family systems theory, and historical trauma theory can be further examined. Future studies could include a wider range of ages in an effort to determine the similarities or differences in the medical mistrust levels and healthcare utilization in Black adults. Future studies can also be done to examine the intergenerational transmission of other forms of trauma.



## Appendix A. Abbreviated Medical Mistrust Survey

### Section A: AGE VERIFICATION

Are you between the ages 18-25?

- 1 Yes
- 2 No – (end survey)

### SECTION B: MEDICAL MISTRUST INDEX V2.2 MEASURING MISTRUST IN HEALTHCARE

The following are questions about how you feel about healthcare organizations. Select whether you strongly disagree, disagree, agree or strongly agree.

| Item   | Strongly Disagree | Disagree | Agree | Strongly Agree |
|--|-------------------|----------|-------|----------------|
| B1. You'd better be cautious when dealing with healthcare organizations.                         | 1                 | 2        | 3     | 4              |
| B2. Patients have sometimes been deceived or misled by healthcare organizations.                 | 1                 | 2        | 3     | 4              |
| B3. I trust that healthcare organizations will tell me if a mistake is made about my treatment.  | 1                 | 2        | 3     | 4              |
| B4. Healthcare organizations often want to know more about your business than they need to know. | 1                 | 2        | 3     | 4              |
| B5. When healthcare organizations make mistakes they usually cover it up.                        | 1                 | 2        | 3     | 4              |



|   |                   |          |       |                |
|---|-------------------|----------|-------|----------------|
| (Section B. Table contd.)   |                   |          |       |                |
| Item  | Strongly Disagree | Disagree | Agree | Strongly Agree |
|   | 1                 | 2        | 3     | 4              |
| B6. Healthcare organizations have sometimes done harmful experiments on patients without their knowledge. |                   |          |       |                |
| B7. The patient's medical needs come before other considerations at healthcare organizations.             | 1                 | 2        | 3     | 4              |
| B8. Healthcare organizations are more concerned about making money than taking care of people.            | 1                 | 2        | 3     | 4              |
| B9. Healthcare organizations put the patient's health first.  | 1                 | 2        | 3     | 4              |
| B10. Healthcare organizations don't always keep your information totally private.                         | 1                 | 2        | 3     | 4              |
| B11. Patients should always follow the advice given to them at healthcare organizations.                  | 1                 | 2        | 3     | 4              |

|  |                   |          |       |                |
|--|-------------------|----------|-------|----------------|
| B12. I typically get a second opinion when I am told something about my health.<br>(Section B. Table contd.)             | 1                 | 2        | 3     | 4              |
| Item   | Strongly Disagree | Disagree | Agree | Strongly Agree |
| B13. I trust that healthcare organizations check their staff's credentials to make sure they are hiring the best people. | 1                 | 2        | 3     | 4              |
| B14. They know what they are doing at healthcare organizations.  | 1                 | 2        | 3     | 4              |
| B15. Sometimes I wonder if healthcare organizations really know what they are doing.                                     | 1                 | 2        | 3     | 4              |
| B16. Mistakes are common in healthcare organizations.  | 1                 | 2        | 3     | 4              |
| B17. I trust that healthcare organizations keep up with the latest medical information.                                  | 1                 | 2        | 3     | 4              |

## SECTION C HEALTHCARE UTILIZATION (17-ITEMS)

C9a. Do you have a regular doctor or other health professional, such as a nurse or a midwife, you usually go to when you are sick or need health care?

- 1 Yes
- 2 No – (SKIP TO C14)
- 3 Has more than one regular doctor (voluntary)

- 8 Don't know
- 9 Refused

C10. Think of your last visit with your regular doctor, would you say the doctor treated you with a great deal of respect and dignity, a fair amount, not too much, or none at all?

- 1 Great deal
- 2 A fair amount
- 3 Not too much
- 4 None at all
- 8 Don't know
- 9 Refused

C11. Would you say that the doctor spends as much time with you as you wanted, almost as much as you wanted, less than you wanted, or a lot less than you wanted?

- 1 As much as wanted
- 2 Almost as much
- 3 Less than wanted
- 4 A lot less than wanted
- 8 Don't know
- 9 Refused

C12. Would you say that the doctor involves you in decisions about your care as much as you wanted, almost as much as you wanted, less than you wanted, or a lot less than you wanted?

- 1 As much as wanted
- 2 Almost as much
- 3 Less than wanted
- 4 A lot less than wanted
- 5 More than I wanted (voluntary)
- 8 Don't know
- 9 Refused

C13. Overall, how satisfied or dissatisfied are you with the quality of health care you have received? Would you say you are very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied?

- 1 Very satisfied

- 2           Somewhat satisfied
- 3           Somewhat dissatisfied
- 4           Very dissatisfied
- 8           Don't know
- 9           Refused

C14. During the last 12 months, was there any time when you had a medical problem but put off, postponed, or did not seek medical care when you needed it?

- 1           Yes
- 2           No
- 8           Don't know
- 9           Refused

C15. During the last 12 months, was there any time when you had a medical problem but never sought any medical attention about your condition?

- 1           Yes
- 2           No
- 8           Don't know
- 9           Refused

C16. During the last 12 months, was there any time when you did not fill a prescription for medicine?

- 1           Yes
- 2           No
- 8           Don't know
- 9           Refused

C17. During the last 12 months, was there any time that you did not come back for a follow up appointment that your doctor gave you?

- 1           Yes
- 2           No
- 8           Don't Know
- 9           Refused

C18. Has there been a time in the last 12 months when you didn't follow the doctor's advice, or treatment plan, get a recommended test or see a referred doctor?

- 1 Yes, has been a time
- 2 No, has not been such a time
- 8 Don't know
- 9 Refuse

C19. If you could choose, would you prefer to be treated by a doctor who is male or female or do you have no preference?

- 1 Male doctor
- 2 Female doctor
- 3 No preference
- 4 Depends on type of doctor/if an ob/gyn (voluntary)
- 8 Don't know
- 9 Refused

C20. If you could choose, would you prefer to be treated by a doctor of your own race or ethnic group, another race or ethnic group, or do you have no preference?

- 1 Own race or ethnic group
- 2 Another race or ethnic group
- 3 No preference
- 8 Don't know
- 9 Refused

#### SECTION D: NEGATIVE EXPERIENCES WITH THE HEALTHCARE SYSTEM

##### Part I: Yourself

D1. Have you ever had a healthcare experience where you were physically harmed or mistreated?

1- No (go to Part II)

2- Yes

D1a. Were you physically harmed or mistreated?

1- Harmed

2-Mistreated

D1b. How long ago was that experience?

- 1- Less than 1 year ago
- 2- 2-5 years ago
- 3- 6-10 years ago
- 4- 11 + years ago

D1c. At the time how, much did that experience bother you?

- 1- None
- 2- Some
- 3- A lot

D1d. Does it still bother you now?

- 1- None
- 2- Some
- 3- A lot

D1e. Did you do anything about it?

- 1- Yes
- 2- No

Part II: Relatives

D2. Has any close relative had a healthcare experience where they were physically harmed or mistreated?

1- No (go to Part III)

2- Yes

D2a. Was that person physically harmed or mistreated?

1- Harmed

2- Mistreated

D2b. How long ago was that experience?

- 1- Less than 1 year ago
- 2- 2-5 years ago
- 3- 6-10 years ago
- 4- 11 + years ago

D2c. At the time, how much did that experience bother you?

- 1- None
- 2- Some
- 3- A lot

D2d. Do you still think about it now?

- 1- Yes

2- No

Part III: Friends

D3. Has any close friend had a healthcare experience where they were physically harmed or mistreated?

1- No (go to section E)

2- Yes

D3a. Was that person physically harmed or mistreated?

1- Harmed

2- Mistreated

D3b. How long ago was that experience?

1- Less than 1 year ago

2- 2-5 years ago

3- 6-10 years ago

4- 11 + years ago

D3c. At the time, how much did that experience bother you?

1- None

2- Some

3- A lot

D3d. Do you still think about it now?

1- Yes

2- No

E. HEALTH BEHAVIOR

Commwealth Survey, Survey on Disparities in Quality of Health Care: Spring 2001

In the last two years, have you had a complete physical exam by a doctor or other health professional?

1- Yes

2- No

SECTION G: PERCEIVED RACISM INDEX FROM CARDIAC ACCESS STUDY

For each of the following statement please tell me if you: Strongly Agree, Agree, Disagree or Strongly Disagree

|  | Strongly Agree | Agree | Disagree | Strongly Disagree |
|--|----------------|-------|----------|-------------------|
|  |                |       |          |                   |

|  |   |   |   |   |
|--|---|---|---|---|
| G1. Doctors treat African American and white patients the same.                        | 1 | 2 | 3 | 4 |
| G2. Racial discrimination in a doctor's office is common                               | 1 | 2 | 3 | 4 |
| G3. In most hospitals, African Americans and & whites receive the same kind of care.   | 1 | 2 | 3 | 4 |
| African Americans can receive the healthcare they want as equally as white people can. | 1 | 2 | 3 | 4 |



## **Appendix B. Interview Questions**

1. How comfortable do you feel when going to the doctor?
2. When you receive medical advice, do you feel the need to get a second opinion prior to following it?
3. What do you think influenced your level of trust in the healthcare system the most?
4. What conversations have your parents/guardians had with you regarding the healthcare system?
5. What do you know about the history of medical racism in the US?
6. Where did you learn information about the history of medical racism in the US?
7. What relationship do your parents have with the US healthcare system?
8. Have you personally experienced what you perceived as medical racism? Describe the incident.
  - a. How did/does it affect you?
9. Have any of your close relatives experienced what they perceived as medical racism? Describe the incident.
  - a. How did you feel when you heard about this?
10. How have these incidents or lack thereof affected your level of trust in the US healthcare system?
11. Do you believe that medical racism still exists within the US healthcare system? Why or why not?
12. If you could choose, would you prefer to be treated by a doctor of your own race or ethnic group, another race or ethnic group, or do you have no preference? Why?
  - a. Are doctors that fit your preference easily accessible?
13. How do you feel your race affects your medical experiences?

## Appendix C. Consent Form

Study Title: Attitudes About the US Healthcare System

1. The purpose of this study is to examine how African American young adults feel about the US healthcare system. The responses will be used to complete a graduate thesis project. The survey should not take more than 10 minutes and the interview about 20-30 minutes. Participants will be audio or video recorded, and these recordings will be stored in a secure database and deleted after March 2023.
2. Risks: There are no risks involved in participating in the study.
3. Investigators: The following investigators are available for questions about this study:

Destiny Jelks, Student Researcher at [djelks1@lsu.edu](mailto:djelks1@lsu.edu)

Dr. Laura Ainsworth, Committee Chair, at [lainsworth@lsu.edu](mailto:lainsworth@lsu.edu)

5. Performance Site: Qualtrics and Zoom
6. Number of subjects: 10
7. Inclusion Criteria: The participants are young adults aged 18-25 who do not report psychological or neurological conditions.
8. Exclusion Criteria: Individuals who are not young adults aged 18-25. Individuals with psychological or neurological conditions.
9. Right to Refuse: Subjects may choose not to participate or to withdraw from the study at any time without penalty or loss of any benefit to which they might otherwise be entitled.
10. Privacy: Results of the study may be published, but no names or identifying information will be included in the publication. Subject identity will remain confidential unless disclosure is required by law.
11. Mental Health Support Services:
  - a. LSU Student Health Center: <https://www.lsu.edu/shc/mental-health/mhshome.php> 225-924-5781
  - b. Crisis Services: <https://crisisservices.org/> ; 716-834-3131
12. Signatures: The study has been discussed with me and all my questions have been answered. I may direct additional questions regarding study specifics to the investigators. For injury or illness, call your physician, or the Student Health Center if you are an LSU student. If I have questions about subjects' rights or other concerns, I can contact Alex Cohen, Institutional Review Board, (225) 578-8692, [irb@lsu.edu](mailto:irb@lsu.edu), or [www.lsu.edu/research](http://www.lsu.edu/research). I agree to participate in the study described above and acknowledge the investigator's obligation to provide me with a signed copy of this consent form.

Subject Signature: \_\_\_\_\_

Date: \_\_\_\_\_

13. The study subject has indicated to me that he/she is unable to read. I certify that I have read this consent form to the subject and explained that by completing the signature line above, the subject has agreed to participate.

Signature of Reader: \_\_\_\_\_ Date: \_\_\_\_\_

**For research involving the collection of identifiable private information or**

**identifiable biospecimens one of the following must be listed on the consent form:**

Identifiers might be removed from the identifiable private information or identifiable biospecimens. After removal, the information or biospecimens may be used for future research studies or distributed to another investigator for future research studies without additional informed consent.

Yes, I give permission \_\_\_\_\_  
Signature

No, I do not give permission \_\_\_\_\_  
Signature

**OR**

Your information or biospecimens collected as part of the research, even if identifiers are removed, may be used or distributed for future research.

Yes, I give permission \_\_\_\_\_  
Signature

No, I do not give permission \_\_\_\_\_  
Signature

## Appendix D. Demographic Questionnaire

Date\_\_\_\_\_

Instructions: *Please answer the questions below. All answers will be kept strictly confidential and your name will not be attached to this form.*

- |    |                             |    |    |        |    |      |    |       |    |
|----|-----------------------------|----|----|--------|----|------|----|-------|----|
| 1. | Your Gender: (Indicate One) |    |    |        |    |      |    |       |    |
|    |                             |    |    | Female |    | Male |    | Other |    |
| 2. | Your Age: (Indicate One)    | 18 | 19 | 20     | 21 | 22   | 23 | 24    | 25 |

## **Appendix E. Recruitment Email**

Hello,

My name is Destiny Jelks and I am a second year student in LSU's Child and Family Studies program. I am conducting an IRB-approved research project that focuses on the attitudes about the US healthcare system amongst African American young adults. I am Seeking African American individuals 18-25 years of age to participate in this study. The responses will be used to complete a graduate thesis project. The survey should not take more than 10 minutes and the interview about 20-30 minutes. Participants will be audio or video recorded. For your participation, you have the option to be entered in a drawing for \$25. All participation is VOLUNTARY and all responses will be kept CONFIDENTIAL.

If you have questions or are interested in participating, please email me at [djelks1@lsu.edu](mailto:djelks1@lsu.edu).

Survey Link:

Thank you for your consideration!

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### **Vita**

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