Adequacy of the Informed Consent Process in Properly Serving the Black Community in Charlottesville

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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I. Introduction

Informed consent is a necessary ethical and legal requirement vital to healthcare and the field of medicine. It is a process that takes place before a patient undergoes a medical procedure or research study. Its purpose is to inform the patient of all aspects of a potential study or procedure they may engage in, so they are able to make an educated, voluntary decision to participate or not (Nijhawan et al., 2013). However, the process of informed consent in medical research and procedures has been a point of contention both throughout history and now for many reasons, one being its unethical reputation with minority communities. My research paper addresses the disconnect between the informed consent process and the Black community. While informed consent in theory has positive intentions, its execution has failed to consistently and properly serve the people it intends to help.

My research specifically addresses the relationship between informed consent and the Black community in Charlottesville. While there are many places in the United States where the efficacy of informed consent and medical research fail to benefit the Black community, I select Charlottesville for its unique racial history tied to the University of Virginia. The relationship between the city of Charlottesville and the Black community is rather muddy and complicated. History including the Black enslaved laborers building the University of Virginia and the alt-right rally in 2017 exemplify a long-standing, continuous culture of mistreatment and disrespect. Furthermore, UVA has been a key academic hub for years, especially for scientific research such as eugenics. The founder of UVA, Thomas Jefferson, also held strong, harmful opinions on the humanity and rights of Black individuals, which he implemented into his university. This ideology in combination with the scientific research being done led to inadequate medical treatment on behalf of the Black community. My research explores the ways in which this history manifests in medical practices both in the past and present of Charlottesville.

First I conduct a literature review which encompasses both the history and current state of the relationship between the informed consent process and the Black community. I also conduct a literature review of the racial history of Charlottesville. Next I introduce the ethical framework which I use as the backbone of my analysis. The framework I select specifically addresses the inherent and unintentional coding of racism into technologies and society. This framework aligns perfectly with the intentions of my research, as the respective technology is medical research, and the society is Charlottesville. In curating my literature review and conducting my analysis, I gather a host of resources ranging from books, academic journal articles, newspapers, blogs posts, and interviews. These sources aid me in a thorough exploration of the history of informed consent in connection with the Black community, and how it has impacted the modern medical field. In my analysis, I explore the ways in which this history, in combination with the history of racial tension in Charlottesville, has contributed to the treatment of the Black community when it comes to medical procedures. I hope to shed light on racial inequities regarding healthcare quality and outcomes in Charlottesville, which little is known about. The history of violated informed consent and medical racism in Charlottesville has perpetuated a broken relationship between medical research and Black Charlottesville residents.

II. Literature Review

There is a historic disregard for the informed consent process when it comes to medical procedures performed on Black individuals. The first documentation of this disregard dates back to the 1840’s where three teenage African American girls, Anarcha, Betsy, and Lucy, received gynecological experimental procedures without anesthesia under the hand of surgeon Dr. James

Marion Sims (Baptiste, 2022). Dr. Sims documented the vesicovaginal fistula repair surgery he performed on Anarcha more than thirty times, Betsy was restrained while being subjected to conditions similar to torture, and he described Lucy’s agony as “extreme” (Sims, 1884, p. 238) as her procedures nearly killed her. Dr. Sims invented the vaginal speculum from these experiments with little critique or backlash for his method. Despite the utilization of these Black bodies, these non consensual experiments would only end up benefiting white women at the time as they were the only ones with access to medical care.

One cannot have a discussion of violated informed consent without mentioning the infamous Tuskegee Study. It began in 1932 when the US Public Health Service (USPHS) issued an experiment in Macon County, Alabama to study the course of untreated syphilis, with the chosen test population to be a group of 400 Black men. In the 1950s when penicillin, a treatment for syphilis, became widely available, it was not given to the test subjects nor was the experiment halted. In fact, the USPHS even tried to withhold treatment from the men. Even a committee under the Center for Disease Control greenlit the continuation of the experiment in 1969. It was not until 1972 that the Department of Health, Education and Welfare forced the experiment to be shut down. Unfortunately, at this point twenty-eight confirmed and possibly more than one hundred of the Black men involved in the experiment had died from syphilitic lesions (Brandt, 1978).

Another more well-known recent example of this disregard for informed consent is the case of an African-American woman by the name of Henrietta Lacks. In 1951, Lacks visited John Hopkins Hospital for treatment for vaginal bleeding. As she lay dying, her cells were removed from her body without her permission, creating the first cell line to survive outside of the body. Her cells, known as HeLa cells, have provided treatment for a host of diseases such as polio, HIV, and several types of cancer (Nisbet et al., 2013). These are just a few examples of a long-running pattern of the disregard and disrespect for Black bodies when it comes to medical research. This attitude toward Black individuals and years of mistreatment have led to a strained relationship between the field of medical research and the Black community.

The historic disregard for the autonomy of Black people has led to a collective apprehension toward experimental medical procedures. In 1997, focus interviews were conducted with African American adults to discover what factors served as barriers to participation in medical research. Many expressed an attitude of their racial group being seen as a “guinea pig” in these experiments (Corbie et al., 1999). Participants offered examples of this exploitation to support their sentiments. They also expressed concern about full transparency regarding risks and required procedures involved with the research. Overall there was a lack of faith in the informed consent process and instead a belief that it was a way for doctors and hospitals to absolve themselves from legal responsibility. Many participants referenced the Tuskegee Study throughout their interview (Corbie et al., 1999). The ideas presented in these interviews corroborate with the current racial dynamics in medical research. Since Black people are overall less likely to participate in research studies, there is less data to work with and it is therefore harder to make population-specific conclusions from clinical trials (Campell, 2021). The strained relationship between the Black community and the medical field has led to real consequences for research development. In 2020, Black African Americans only made up 8% of participation in clinical trials (Allison et al., 2022). While the Tuskegee Study is the most well-known, there are countless other factors that influence the current racial issues in the medical field.

Due to Black people historically being thought of as less intelligent, cooperative and compliant, healthcare providers now associate Black patients as falling under these stereotypes and being non-compliant and less cooperative than white patients (Madeira et al., 2022). Additionally, racial and ethnic bias contribute to Black Americans receiving lower quality healthcare than white Americans. For example, Black patients are less likely than white patients to be recommended for surgery for oral cancers. On the flip side, Black people are also more likely to be recommended to undergo unnecessary procedures (Dovidio et al., 2012). While these are general racist ideals that have been held nationally, each city also has its own specific story.

Charlottesville is a city with a rich history of systematically engrained racism. President Thomas Jefferson, who used enslaved laborers to build the University of Virginia, wrote in his book *Notes on the State of Virginia* that Black people are “inferior to the whites in the endowment both of body and mind” and denied that Black people experienced love or sorrow (Mathew, 2019, p. 274). This culture was perpetuated at the University of Virginia and the surrounding city for years after Jefferson’s presence. This dehumanization manifested itself in Charlottesville city government laws that limit Black residents’ equal access to clean air, clean water, decent shelter, and adequate health care (Matthew, 2019).

Residential segregation in Charlottesville enables institutionalized racism (Matthew, 2019). It creates a space where white supremacy is comfortable, as was made evident by the white nationalist march that took place on the University of Virginia campus in August of 2017 that promoted ideals of an exclusively white nation. One counterprotestor, Montae Taylor, recalls how police turned an eye to white supremacists provoking Black counter protestors, and the National Guard were quick to point their weapons toward peaceful counter protestors

(Colvin, 2017). The difference in treatment by the largely Black counter protestors and the white supremacists is symbolic of the racial divide in Charlottesville.

Conceptual/Theoretical Framework

The theoretical framework I utilize in my analysis is Ruha Benjamin's "New Jim Code" framework from her work *Race After Technology: Abolitionist Tools for the New Jim Code*. Under this framework, she presents the idea that technology and society cannot exist apart, they are instead intertwined. She redefines race from a rather novel lens. She makes the claim that race is not simply an element of society, but "a set of technologies that generate patterns of social relations, and these become Black-boxed as natural, inevitable, automatic" (Benjamin, 2019, p. 34). Furthermore, anti-Black racism is both a precondition and an outcome for the development of technologies fueled by capitalism.

The technology being fueled by capitalism that I discuss in my research is medical research. I specifically focus on capitalism's exacerbation of power differentials between different social groups. In this case, the imbalance is between the white academics and scientific leaders at UVA and the Black community in Charlottesville. I explore the role this unbalanced power-dynamic plays in spearheading the anti-Blackness embedded within this technology in Charlottesville. I use Benjamin's framework in my analysis of the efficacy of informed consent for the Black community in Charlottesville to understand race as a technology in the field of medical research, which helps me identify the social patterns that have contributed to current disparities regarding informed consent for Black individuals. Using her work, I contribute to current research by identifying specific inequities rooted in both medical and systemic racism in Charlottesville. While these inequities have been identified in the past, they have not been studied under the context of a specific location. I believe adding this additional element offers analysis regarding medical racism that is more tailored to the problems with informed consent experienced by vulnerable groups in that area. Therefore, by understanding the system, I can offer an analysis that might hit the root of the issue rather than just scratching the surface.

III. Methods

My research involved an exploration into three different topics, therefore I divided it into three parts. I explored the history of racism in relation to informed consent in the medical field, the history of racism in Charlottesville, and lastly a combination of the two; medical racism in Charlottesville. In order to do this, I gathered academic journal articles and media and journalistic reports such as newspapers, tabloids, and news articles.

In my review of this literature, I took a historical analysis approach. The overarching goal of this section was to examine social factors and power structures, with a focus on the role of race in decisions made in the medical field and the racial history of Charlottesville. I relied heavily on academic journal articles for this portion of my research. I wanted to examine evidence from the past to understand both its influence then and on the present. I created a short timeline highlighting key events in the progression of informed consent in relation to the Black community to set up the landscape for my analysis. This primarily involved collecting academic journal articles and books on the topic. After providing a historical overview of the topic, I sought to highlight its current effects and implications on modern society. This involved collecting academic studies and journals related to the current state of medical research with regards to the Black community. In researching Charlottesville's history, I also collected scientific studies performed with African American particpants to shed light on the topic from a more primary source. I used content from African American newspapers like The New Journal and Guide, a news source originated in Virginia, as a more direct source.

In my analysis section, while still conducting historical analysis, rather than just narrating the events of the past, I shifted the focus towards the relevant social groups affected. I focused on gaining a deeper understanding of the behaviors and beliefs of the Black community in Charlottesville with regards to medical research. I sought out sources detailing research studies of Black people's knowledge, perception, and personal experience with informed consent in medical experimentation, research articles on medical racism, and the history of racism in Charlottesville.

I focused on the UVA Health University Hospital as this is the most well-known hospital in Charlottesville. Despite its current prestige and popularity, the hospital has a rich racial history which I desired to both highlight and explore the implications of in my analysis. This history adds an extra dimension to my analysis. In order to uncover the racial history of Charlottesville and capture the Black medical experience in Charlottesville, I used national and local news sources. I specifically selected articles written by Black authors to ensure their perspective on these issues which directly affect them are captured. UVA Health also has specific information and an exact timeline of the history of medical racism in the UVA hospital which I utilized in my research.

IV. Analysis

By engaging in unethical research practices, medical leaders in Charlottesville created a culture of racism and discrimination against Black individuals in the area. The city had great power and social standing due to the influence of the third president of the United States, Thomas Jefferson, who both lived and founded the University of Virginia there in 1819. The university became a central location for scientific research, attracting brilliant scientists and professors. One of the sciences in which Charlottesville became a significant hub for was eugenics. As defined by the *American Journal of Sociology*, "eugenics is the science that deals with all influences that improve the inborn qualities of a race; also with those that develop them to the utmost quality" (Galton, 1904, p. 1). The University of Virginia was considered the primary eugenics hub of the south in the 19th and 20th century, and Thomas Jefferson was greatly intrigued by this race science (Reynolds, 2023).

Thomas Jefferson did not shy away from expressing his views of African American people. Of his enslaved laborers he remarked they were "lacking beauty; emitting a very strong and disagreeable odor; were in reason, inferior; in imagination were dull, tasteless, and anomalous; participated more in sensual activity than reflection; never conversed in thought above the level of plain narrative; and were never seen producing even an elementary trait of painting or sculpture" (Dorr, 2008, p. 27). Ruha Benjamin (2019) explains New Jim Code as "an era, a geographic region, laws, institutions, customs, and a code of behavior that upholds White supremacy" (p. 9). As founder of the university, Jefferson's code of behavior was embedded into its infrastructure. Due to Jefferson's influence, overtly harmful and demeaning views of Black people were indoctrinated into the university's curriculum throughout the 19th and 20th century (Reynolds, 2023).

The University of Virginia actively worked to ensure Black people were perceived as inferior both biologically and from a human rights perspective. Thomas Jefferson argued that "any attempt to assimilate [Blacks] with the American polity is a greater threat to the integrity of the republic than naturalizing immigrants" (Dorr, 2008, p. 27). The first professor of medicine at UVA, Robley Dunglison, identified supposed anatomical differences between Blacks and whites and used this as justification for racial differences in the classes he taught (Reynolds, 2023).

Faculty member Paul Brandon Barringer contributed greatly to the crafting and spread of eugenics ideas at UVA, and also commissioned the building of the same UVA Health hospital that is still in popular use today (Reynolds, 2023). It was not until 1965 that the federal government insisted that the hospital officially announce it was desegregated. Although it had been partially desegregated a few years prior, many Black patients were not even aware of this (Marshall, 2022).

While the UVA Health hospital was a staple of Charlottesville's medical infrastructure, the Black community did not experience the full extent of its benefits. The origins of medical services in Charlottesville failed to properly serve the Black community. On the outside, the UVA Health hospital appeared as a prime location for Charlottesville residents to receive quality medical attention. Instead, Black people were subjected to subpar conditions and treatment. Black patients were segregated in this hospital, and could only be treated in the basement wards where they were exposed to open rooms, leaking pipes, and peeling paint. The sick and mentally ill were all housed together, further complicating treatment. Furthermore, highly restricted ambulatory and surgical care skyrocketed morbidity and mortality rates from contagious and chronic illnesses (Marshall, 2022).

Outside of just the hospital, as a whole, less medical care and attention was given to Black residents as a direct result of their race. After emancipation, a popular belief pushed at the time was that Black people had devolved to their original savage nature which made them more predisposed to disease and crime (Marshall, 2022). As a consequence of this logic, although Black people experienced abnormally high rates of tuberculosis, syphilis, and typhoid fever, this was simply brushed off as proof of their genetic inferiority (Marshall, 2022). To add injury to insult, in 1924, the Virginia Sterilization Act and the Racial Integrity Act were passed which in effect magnified the principles of Jim Crow, denying Black people medical care, jobs, sufficient pay, higher education, and professional training (Marshall, 2022). Documents from the 1930s and 1940s recognize the disparity in treatment between white and Black Charlottesville residents as evidence shows Black patients received significantly less and in some cases no care when there were viable treatment options (Reynolds, 2023).

Promoting and engaging in unethical research practices that denied Black people their right to informed consent was a prevalent issue in Charlottesville's history. Even after death, Black bodies were disrespected and used to further medical research. In 1825, Thomas Jefferson commissioned the erection of a building he designed known as the Anatomical Theatre, which served the purpose of storing cadavers and being a classroom for anatomy classes. Professors such as John Steige Davis used bodies of African American individuals stolen from their graves as the primary source of cadavers. These bodies were offered full range of access and experimentation to students. (Matson, 2021). Jefferson also endorsed the denial of Black people to informed consent. In his book *Notes on the State of Virginia*, Jefferson wrote about the Black population that to "justify a general conclusion requires many observations, even where the subject may be submitted to the Anatomical knife, to Optical glasses, to analysis by fire, or by solvents" (Jefferson, 1832, p. 153).

The history of medical racism has contributed to apprehension Black residents of Charlottesville now feel when it comes to their autonomy. Residents in Charlottesville refer to well-known examples of informed consent violations for the Black population in support of their skepticism. Referring to the Tuskegee Study, Black Charlottesville resident Sheleigha Early remarked, "the Black community has not had the greatest record regarding vaccines within the medical field" when asked about her opinions on the COVID-19 vaccine (Louis, 2020, p. 1).

Specific instances of disrespected autonomy in Charlottesville also influence this skepticism. Years of racism and medical mistreatment has become encoded into informed consent. Eugenics work still occurred in the 1970s in which minority groups were targeted for sterilization. Dr. Ebony Jade Hilton, an associate professor of anesthesiology and critical care at UVA remarked on the issue, “Black women were heavily targeted for sterilization, where they’d go to the hospital and leave without their uteri” (Louis, 2020, p. 1). This apprehension is evident when it comes to current medical research and procedures. In 2020 when the COVID-19 vaccine was becoming available for public use, many Black Charlottesville residents expressed distrust in fear of being “treated as guinea pigs” (Louis, 2020, p. 1). The racial history of Charlottesville has created a schism between the efficacy of medical research and the Black community. Many Black residents are quite guarded when it comes to trusting the medical practitioners. Sheleigha Early also commented, “I don’t think that there’s one thing that the medical community in Charlottesville can do to ease the fear or concerns that African Americans have” (Louis, 2020, p. 2).

The presence of New Jim Code is evident, as outdated ideas rooted in racism are still present in the medical field in Charlottesville. In 2016, a study published by the University of Virginia showed that a great number of white medical residents and students at UVA thought Black patients were biologically different than their white counterparts citing beliefs that their skin was thicker and nerve endings less sensitive (Hausman, 2019). This led to underwhelming treatment of pain for Black patients. This same study also revealed that almost 21% of first-year medical students believed Black people had stronger immune systems than white people (Stith, 2022). It also found that 15% of second-year medical students thought Black couples were more fertile than white couples (Stith, 2022).

There is an inharmonious relationship between Black people and the healthcare practitioners who are supposed to care for them. Irene Mathieu, a doctor and chair for the Equity and Inclusion Committee at UVA's Department of Pediatrics, asserts that, "Patients of color tend to both show up more when there is a physician of color and also to follow the advice of physicians of color more than they follow the advice of white physicians, so it seems like there's a difference in trust there" (Hausman, 2019, p. 2). Based on the University of Virginia study from 2016 mentioned above, practitioners who held these beliefs were less accurate 15% of the time in recommending treatment (Stith, 2022).

Some may argue that the failure of informed consent to serve its intended goal is not influenced by race, but instead a problem with its structure. They would argue that a heavy reliance on physician proficiency of informed consent has hindered its success. Physicians overall receive limited training on how to conduct the informed consent process, they may be operating on a condensed time window, or have external demands preventing thorough conduction ("Quick Safety 21", 2022). Furthermore, informed consent forms often lack the required elements. Informed consent is required by the Joint Commission, a national healthcare-organization accreditation organization, to contain five essential elements (Shah et al., 2023, p.1). Yet, a research study found that the first four of these elements only appeared in consent forms 26.4% of the time ("Quick Safety 21", 2022). If a patient experiences an inadequate informed consent process, it can be attributed to physician incompetence or incomplete documentation rather than the patient's race.

While these issues are true of informed consent, there is also direct evidence of how the failure of informed consent is correlated to race. Past perceptions of Black people have become encoded into informed consent, thereby hindering the efficacy of the process. For example, during slavery, Black women were perceived as more masculine, pain resistant, and stronger than white women. At the same time, they were also seen as weaker, less capable, and less competent (Campbell, 2021). These views of Black women from the past often cause doctors now to either prescribe more or less medication than necessary or perform procedures with an irregular amount of anesthesia. One modern example is the paradox of overmedicalization and medical neglect when it comes to cesarean section operations for Black women. Viewing Black women through this distorted lens has led physicians to present informed consent in such a way that the women are not aware of every possible risk (Campbell, 2021). This is fueled by the underlying racist assumption that Black women can handle whatever is thrown at them.

V. Conclusion

After reading my paper, the reader should have a more comprehensive understanding of the racial history of Charlottesville, specifically with regards to the medical field, and a better understanding of what informed consent is and how it has failed to benefit Black people in the same way as white people. Understanding the historical context of medical racism at the University of Virginia is essential for rectifying the inequities of the past. This research will be beneficial to healthcare practitioners in the UVA hospital to understand the complexity of the infrastructure within which they are operating. It will also allow them to see their work through the lens of the Black community, which might make them more intentional in their treatment of Black patients. This may also enlighten some practitioners to intentional or unintentional bias they may have expressed while working with Black patients. This research could also lead to changes in certain policies or practices regarding medical experimentation that have failed to serve Black/minority populations in Charlottesville.

Future research should look at the history of gender disparities and equality in Charlottesville, and in medical research and experimentation. The analysis would involve pinpointing the ways in which this history influenced the current state of medical experimentation and how this intersectionality has influenced experiences with informed consent for the respective group affected.

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