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Propagation of Southern Antebellum Medical Ideologies: Practitioners' Racism & Black Patients' Mistrust of Medicine in the Modern United States

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Abstract

Propagation of Southern Antebellum Medical Ideologies: Practitioners' Racism & Black Patients' Mistrust of Medicine in the Modern United States

By Henry Ram Mangalapalli

Multiple generations of medical practitioners in the United States abide by logics and attitudes concerning Black patients which hail from antebellum scientific racist thought. These have stood the test of time and remain evident in medical teachings and practice, informing the acceptability of mistreating Black patients within the medical field today. At the same time, due to medical professionals' scarred record of abusing Black bodies, mistrust of practitioners within the Black community similarly dates back to antebellum times. The phenomena of mistreatment and mistrust parallel one another and renew themselves each generation that antebellum medical logics and downgrading of Black patients' worth are propagated. This thesis identifies these patterns manifesting throughout the course of U.S. medical history in 1) clinical practitioners' and researchers' intentional infliction of pain upon Black patients and research subjects, and 2) a history of deliberate neglect of Black patients' healthcare needs at the systemic and individual levels. There exists a plethora of literature detailing Black communities' mistrust in medical practitioners due to either personal experiences or collective trauma, in addition to a large body of literature concerning limits on Black patients' ability to receive healthcare across U.S. history. However, this thesis notes a lack of literature directly linking the pervasiveness of racism through the course of U.S. medical history to the parallel phenomena of mistrust and collective trauma towards medicine in the Black community. Moreover, there is a lack of scholarly attention to the resurfacing of antebellum medical ideologies into medical training and practice in subsequent generations. This thesis draws upon antebellum medical writings and archival documents, secondary literature on the history of medical practitioners' intentional mistreatment of Black patients, modern studies concerning health and mistrust within Black communities, and digital media documenting the dual crises of mistreatment and mistrust for this thesis.

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Introduction

Origins of Mistreatment & Mistrust

Historical Context

In her autobiography recounting her enslavement, Annie Burton recalls two Black men being lynched at the hands of white men in Clayton, Alabama, during her childhood. She recalls,

> Since I have grown up, I have seen the skeleton of one of these men in the office of a doctor in Clayton. After the men were hung, the bones were put in an old deserted house. Somebody that cared for the bones used to put them in the sun in bright weather, and back in the house when it rained. Finally the bones disappeared, although the boxes that had contained them still remained.[1]

Later, she and some other enslaved children were given brandy by a white boy, and doctors were called when they appeared drunk. They were offered castor oil, "but we refused to take it, because we thought that the oil was made from the bones of the dead men we had seen."[2]

Burton's story draws parallels with post-Civil War fears of "night doctors" kidnapping both Black cadavers and living Black people for medical experimentation. While these fears' folkloric origins may result in their easy dismissal, the utilization of mainly Black cadavers by medical schools of the time leaves little speculation as to their merit, let alone the collective trauma related to medical professionals they established within the Black community.[3] [4] Though Burton's account about the making of castor oil is apocryphal, her story is a case in point of fears stoked in African American communities regarding abuses by white medical practitioners. Accounts of grave robbers and the non-consensual and otherwise gruesome utilization of Black cadavers, as Burton witnessed, were frightening enough to drive African Americans to fear hospitals and physicians. A system in which Black individuals were, and continue to be, utilized

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[1] Annie L. Burton, *Memories of childhood's slavery days* (Boston: Ross Publishing Company, 1909), 5-6.

[2] Burton, *Memories of childhood's slavery days*, 6.

[3] Vanessa Northington Gamble, "Under the Shadow of Tuskegee: African Americans and Health Care," *American Journal of Public Health* 87, no. 11 (1997): 1774-75a.

[4] David C. Humphrey, "Dissection and Discrimination: The Social Origins of Cadavers in America, 1760-1915," Bulletin of the New York Academy of Medicine 49, no. 9 (1973): 819-27.

to the will of white medical practitioners eerily mirrors slavery-era power dynamics in which enslaved Black people were subjected to abuse at the hands of white enslavers.

Relevance to the Modern Era

This thesis is concerned with the question, to what extent do antebellum medical logics inform current medical practice for Black patients, as well as Black communities' ability to trust healthcare professionals? As indicated by Burton's recollection, the mistreatment of Black patients and their dehumanization by medical professionals dates back to the era of chattel slavery and has fueled an understandable mistrust ever since. The reproduction of racism and physician mistrust fuel a vicious cycle of patients experiencing fear–a valid response to trauma–in seeking medical attention, and thus avoiding it altogether, while racial biases going unchecked within the healthcare field stunt the quality of care and right to dignity patients receive. Anxieties about going to the doctor can cause delayed diagnoses and worse outcomes, exacerbating health concerns for a community already carrying a greater risk of cardiovascular disease, many types of cancer, and a greater allostatic load (the cumulative effects of chronic stress as manifested at the biological level) for living in this racist society.

Western medical practices today exhibit many concepts and attitudes rooted in antebellum racial presumptions, a reminder that racism is embedded at the core of Western-based medical professions and knowledge. Metrics of, and assumptions about, Black patients' health based on biases rather than biological facts have seeped into modern medicine from eras past. Modern instruments are still calibrated to indicate a lower baseline lung capacity and intelligence level for Black patients,[5] an extension of baseless beliefs from Old South physicians, eugenicists,

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[5] Will Hobson, "How 'Race-Norming' Was Built into the Nfl Concussion Settlement," *The Washington Post*, August 2, 2021, https://www.washingtonpost.com/sports/2021/08/02/race-norming-nfl-concussion-settlement/; Meredith A. Anderson et al., "Could Routine Race-Adjustment of Spirometers Exacerbate Racial Disparities in Covid-19 Recovery?", *The Lancet Respiratory Medicine* 9, no. 2 (2021): 124-25

Social Darwinists, and early biological anthropologists, whose concerns resided more in idealizing the Black body for servitude rather than good health.[6] This subject became of concern recently during an investigation in which the NFL requested that doctors lower the baseline cognition level for Black players showing symptoms of concussion and brain damage. This was a clear attempt to systematically lower the league's culpability in failing to prevent head injuries.[7] What may seem to be an old, outdated presumption steeped in racist antebellum ideologies still lives strong, to ensure that Black patients do not.

As historians, modern researchers, and modern narratives of Black patients have demonstrated, physicians have long neglected the pain of Black people. The best case study for this is Dr. J. Marion Sims' lack of documentation as to whether his experiments caused pain to his victims,[8] despite the nature of the procedures leaving little room to predict that pain was not felt. In 2016, a study conducted by researchers at University of Virginia demonstrated that half of the surveyed medical students believed Black patients feel pain differently than white patients.[9] Though there is no telling whether these beliefs originated prior to or during their tenure as medical students, the pattern is obvious: gross misconceptions about Black pain get recycled in each new generation of doctors. A particularly revealing incidence of this reality is the 2016 case of Kira Johnson, a Black mother whose catheter was draining blood within hours of her Cesarean section before she bled to death after doctors denied her emergency surgery for an additional 10

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[6] Ayres P. Merrill, "An Essay on Some of the Distinctive Peculiarities of the Negro Race," *Southern Medical and Surgical Journal* 12 (January 1856): 22-23.

[7] Hobson, "'Race-Norming.'"

[8] J. Marion Sims, *The Story of My Life* (New York: D. Appleton and Company, 1884).

[9] Kelly M. Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs About Biological Differences between Blacks and Whites," *Proceedings of the National Academy of Sciences of the United States of America* 113, no. 16 (2016): 4296-301, https://dx.doi.org/10.1073/pnas.1516047113.

hours, the final 6 of which she was classified a "surgical emergency."[10] Had doctors acted quicker–and seen the need–to act, Johnson would have lived to see her child grow up.

Not only are racist assumptions about Black physiology and dismissal of symptoms killing Black patients–the medical curriculum is, too. There is increasing recognition in medical circles and published findings regarding the diminished quality of care afforded to Black patients due to a lack of inclusivity in medical curricula, issues accessing healthcare in Black communities, and blatant racism by medical providers.[11] Tracing the lack of diverse skin tones through generations of Western medical textbooks alone can confirm undeniable links between the racism in medicine of eras past and continued racial bias in the field today. A study published by Patricia Louie and Rima Wilkes in 2018 analyzed medical textbooks and found that very few contain guidelines on symptom manifestation on darker skin tones. In 75% of medical textbooks analyzed in one study, lighter skin tones were overrepresented compared to their proportion in the U.S. population.[12] Ailments such as skin cancer and hypoxia cannot be detected in patients with darker skin tones if healthcare professionals are not trained in how to notice them, leading to later diagnosis and worse prognosis.[13] The lack of skin tone diversity in medical practice and curricula has come up during the COVID-19 pandemic, during which it has been noted that health authorities were notifying those who tested positive that if their lips turned blue, they

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[10] Charles Johnson, "After His Wife Died, Man Pushing to Change Laws to Protect More Women From Pregnancy-related Deaths," *NBC Los Angeles*, July 16, 2020, https://www.nbclosangeles.com/investigations/wife-died-giving-birth-change-laws-to-protect-more-women-pregnancy-related-deaths/2395401/.

[11] Patricia Louie and Rima Wilkes, "Representations of Race and Skin Tone in Medical Textbook Imagery," *Social Science & Medicine* 202 (Apr 2018): 40; Smedley, Stith, and Nelson, eds., "Introduction and Literature Review," 29; Johnson, "Pregnancy-related Deaths."

[12] Louie and Wilkes, "Representations," 41.

[13] Michael W. Sjoding et al., "Racial Bias in Pulse Oximetry Measurement," *New England Journal of Medicine 383,* no. 25 (2020): 2477-78, https://dx.doi.org/10.1056/NEJMc2029240; "Skin Cancer & Skin of Color," Skin Cancer Foundation, last updated January 28, 2022, https://www.skincancer.org/skin-cancer-information/skin-cancer-skin-of-color/#:~:text=Squamous%20cell%20carcinoma%20is%20the%20most%20common%20skin%20cancer%20in%20Black%20people.&text=Black%20patients%20with%20melanoma%20have,93%20percent%20for%20white%20patients.&text=Melanoma%20in%20people%20of%20color,that%20get%20little%20sun%20exposure.

should go to the emergency room. However, only fair-skinned individuals' lips can turn blue, leaving Black families without signs to look for that their loved one's life is in danger.[14] With healthcare professionals entering the field unaware of how symptoms manifest differently in those with darker skin tones, Black patients are dealt a bad hand in their likelihood of having their symptoms detected and attended to in a timely manner.

All in all, healthcare systems and healthcare professionals are programmed to function in ways which systematically guarantee lower quality of care and worse outcomes to Black patients, in addition to denying them the respect owed to all patients. The legacy of mistrust transcending multiple generations of Black patients, in addition to the recycling of racist medical ideologies and attitudes among physicians, illustrate a tradition of accepting poor, unethical treatment of Black patients while ignoring their healthcare needs. This is not an invitation to place blame for physician mistrust on the shoulders of patients, but rather a challenge to face the patterns of medical wrongdoings which validate apprehension towards the healthcare system.

Racism in Medical Curriculum

There is an existing body of scholarship which has recognized the longstanding implications of mistreating Black individuals within the medical field. The most substantial consequences of mistreatment are Black patients holding fear in seeking even life-saving treatment and generations of medical practitioners adhering to racist attitudes and practices, such as dismissing Black patients' pain or need for treatment and lying about the true nature and purpose of medical research. For example, Karnieli-Miller et al. describes the "hidden curriculum"[15] underlying much of the racism seen in medical practice as incorporated during

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[14] Caroline Tien, "Covid-19 Symptom Lists and Detection Tools May Exhibit Racial Bias," Verywell Health, December 30, 2020, https://www.verywellhealth.com/covid-symptom-detection-racial-bias-5093649#:~:text=Key%20Takeaways,patients%20compared%20to%20White%20patients.

[15] Orit Karnieli-Miller et al., "Which Experiences in the Hidden Curriculum Teach Students About Professionalism?", Academic Medicine 86, no. 3 (2011): 369, 10.1097/ACM.0b013e3182087d15.

aspects of training which “influence students' socialization into the norms and rituals of the organization, teach the conventions of interpersonal processes between students and teachers and patients and physicians, and demonstrate the complexities of relationships with other professionals.” If a medical, nursing, or other trainee in the healthcare field witnesses practitioners consistently and intentionally mistreating Black patients, they will internalize that behavior as tolerable and acceptable once they become fully-certified practitioners themselves. The “hidden curriculum”[16] furthermore necessitates an existing culture of anti-Blackness interwoven with American medicine which enabled practitioners who are training those who will follow in their footsteps to be racist - implicitly or explicitly - during interactions with patients.

Racialized Mistrust

In 2003, Saha et. al.[17] investigated whether racial differences in patients’ satisfaction with physicians were correlated with their use of health services, and is considered a major study in gauging the depth of physician mistrust and patients’ preference for racial concordance between them and their physicians (meaning that the physician and patient identify as the same race). There are, however, major differences within Saha’s research compared with other studies. For example, Saha reported that among four racial groups participants were categorized into – Black, white, Hispanic and Asian – Black patients were the least likely to state a preference for a physician of their own race (5.6%),[18] are the most likely to report their physician fully listens to them (69.3%),[19] and are the most likely to have recently received screenings and exams for cancer, diabetes, and high blood pressure. Geographically, most (58.1%) of the study’s Black

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[16] Karnieli-Miller et al., “Which Experiences in the Hidden Curriculum,” 369.

[17] Somnath Saha, Jose J. Arbelaez, and Lisa A. Cooper, "Patient–Physician Relationships and Racial Disparities in the Quality of Health Care," American Journal of Public Health 93, no. 10 (2003): 1713-19, https://dx.doi.org/10.2105/ajph.93.10.1713

[18] Saha, Arbelaez, and Cooper, “Patient–Physician Relationships,” 1715a.

[19] Saha, Arbelaez, and Cooper, “Physician–Patient Relationships,” 1715b.

participants hailed from the South,[20] adding further speculation about the accuracy of these results given the South's history as a site of racial violence and as the birthplace of the aforementioned antebellum medical logics built to harm Black patients' health for generations thereafter. The study attempts to explain the greater use of healthcare services as a result of increased efforts to reach Black communities around the time of the study owing to prior findings of healthcare accessibility gaps. It attributes the relative lack of preference for racially-concordant physicians and greater likelihood of feeling that their doctor listens to them to the study only asking about their most recent encounters with physicians. However, other studies[21] report that Black and LatinX patients report the greatest difficulties in securing a consistent physician and healthcare setting, often relying on the emergency room or outpatient centers for care compared to their white counterparts. Additionally, only inquiring about one's most recent encounter with a physician leaves untouched the vast histories and collective traumas underlying Black patients' interactions with healthcare professionals in the U.S. Uncritical use of Saha's study to identify issues within the healthcare system and build better relationships between medical professionals and patients thus runs the risk of reducing Black patients to statistics, rather than addressing the deeper veins of racism embedded into the way medical professionals communicate with them.

To speak directly to how racialized medical mistrust is, a 2007 study by Armstrong revealed that Black patients have higher physician distrust scores than white and LatinX/Hispanic patients.[22] However, this is just the tip of the iceberg. Distrust due to negative

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[20] Saha, Arbelaez, and Cooper, "Physician–Patient Relationships," 1715c.
[21] Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson, eds., "Introduction and Literature Review," in *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academy Press, 2002): 73-74, https://doi.org/10.17226/12875; Qiao, William P. et al., "Relationship between Racial Disparities in Ed Wait Times and Illness Severity," The American Journal of Emergency Medicine 34, no. 1 (2016): 12-14, https://dx.doi.org/https://doi.org/10.1016/j.ajem.2015.08.052.
[22] Katrina Armstrong et al., "Racial/Ethnic Differences in Physician Distrust in the United States," *American Journal of Public Health* 97, no. 7 (2007): 1285, https://dx.doi.org/10.2105/ajph.2005.080762.

past interactions with medical professionals leads to avoidance of medical professionals, as was discovered in a focus group study of reproductive and sexual healthcare services among Black women in Georgia and North Carolina.[23] Because much of an individual's health outcome is based on early detection and prevention, any delay in seeking care–from routine check-ups to having suspicious symptoms examined–leaves fewer options for intervention. African American communities already harbor higher mortality rates from diseases such as cancer,[24] colorectal cancer,[25] and type 2 diabetes,[26] combined with an average life expectancy 4 years lower than that of white Americans.[27] Many Black patients additionally cite concerns and personal experiences in which their physician will not listen to them or recommend them for additional screenings or treatment,[28] dismissing their concerns. Since Black communities' health situations are more precarious than those of white Americans, addressing intentional dismissal of Black patients' symptoms and mistrust of medical professionals, albeit justified, is paramount.

More Than Tuskegee

Some existing literature actively makes the association between past mistreatment and exploitation and modern patterns within the Black community of mistrusting healthcare professionals. Fears of exploitation in medical research following the Tuskegee Syphilis Study in

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[23] Terri-ann Monique Thompson et al., "Racism Runs through It: Examining the Sexual and Reproductive Health Experience of Black Women in the South," *Health Affairs* 41, no. 2 (2022): 199, https://dx.doi.org/10.1377/hlthaff.2021.01422.

[24] Clement G. Yedjou et al., "Health and Racial Disparity in Breast Cancer," *Advances in Experimental* Medicine and Biology 1152 (2019): 34, https://dx.doi.org/10.1007/978-3-030-20301-6_3.

[25] Rebecca Siegel, Carol DeSantis, and Ahmedin Jemal., "Colorectal Cancer Statistics, 2014," CA Cancer Journal for Clinicians 64, no. 2 (Mar-Apr 2014): 109. https://dx.doi.org/10.3322/caac.21220.

[26] Elias K. Spanakis and Sherita Hill Golden, "Race/Ethnic Difference in Diabetes and Diabetic Complications," *Current Diabetes Reports* 13, no. 6 (2013): 815, https://dx.doi.org/10.1007/s11892-013-0421-9.

[27] National Center for Health Statistics. Health, United States, 2019: Table 004. Hyattsville, MD. 2021. https://www.cdc.gov/nchs/hus/contents2019.htm.

[28] Tressie McMillan Cottom, "Dying to Be Competent," in *Thick and Other Essays* (New York: The New Press, 2019), 73-98; Gregory Mansella et al., "Delayed Diagnosis in Pulmonary Embolism: Frequency, Patient Characteristics, and Outcome," *Respiration* 99, no. 7 (2020): 589-97, https://dx.doi.org/10.1159/000508396;Smedley, Stith, and Nelson, eds., "Introduction and Literature Review," 54 & 60.

particular are so widespread that at the National Commission on AIDS in 1990, Dr. Mark Smith stated that Tuskegee "'provides validation for common suspicions about the ethical even-handedness in the medical research establishment and in the federal government, in particular, when it comes to Black people.'"[29] Other studies also cite Tuskegee as a driving factor for Black patients' refusal to participate in medical research, noting specific comments from patients such as Scharff et al.'s 2010 study:

> It [Tuskegee] becomes a symbol of these two portions of my existence and it becomes a way for me to answer the question, why. So me participating in something else that might be like that, why would I do that to myself?[30]

However, Tuskegee alone should not be pinpointed as the origin of medical practitioners' intent to harm Black people. One of the most foundational texts for addressing the role of unethical experimentation on Black people *throughout* U.S. history on the inherited mistreatment of Black patients by medical professionals, and on the inhereted mistrust of medical professionals by Black patients, is Harriet Washington's 2006 book *Medical Apartheid*. This text gives a comprehensive overview of several lesser-known cases of abuse, cruel experimentation, and outright refusal of treatment leveraged against Black patients throughout U.S. history.

At the same time, the disturbing abundance of documented and even rumored experiments that targeted and harmed Black subjects, refusals to be treated properly or at all by doctors, and countless other wrongdoings, are enough to create an association between medicine and harm in the collective conscience of Black Americans. The message is clear: Black patients know that the healthcare system was not built with their health, safety, or dignity in mind.

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[29] Vicki. S. Freimuth et al., "African Americans' Views on Research and the Tuskegee Syphilis Study," Social Science & Medicine 52, no. 5 (2001): 799, https://dx.doi.org/10.1016/s0277-9536(00)00178-7.

[30] Darcell P. Scharff et al., "More Than Tuskegee: Understanding Mistrust About Research Participation," *Journal of Health Care for the Poor and Underserved* 21, no. 3 (2010): 886, https://dx.doi.org/10.1353/hpu.0.0323.

More directly, a 2021 study published by *The New England Journal of Medicine* is cautious about citing specific landmark events as the sole cause of mistrust. In this article, readers are implored to view alarmingly high rates of vaccine hesitancy in Black communities as a consequence of structural racism built into everyday encounters between Black patients and the healthcare system, rather than Tuskegee or another notorious event. Simar Singh Bajaj and Dr. Fatima Cody Stanford write:

> When we hyperfocus on Sims, Lacks, and Tuskegee, we ascribe the current Black health experience to past racism, rooting our present in immovable historical occurrences and undermining efforts to combat mistrust. Everyday racism, by contrast, can be tackled in the present.[31]

This thesis adapts Bajaj & Stanford's framework that while major events such as Tuskegee–and lesser-known cases of experimentation and mistreatment of patients–hit very close to home for a significant number of individuals and do influence their ability to trust the field of medicine, it is important to avoid chalking up all mistrust towards medicine experienced by Black individuals to a handful of high-profile events alone.

Gap in Knowledge & Scholarship

However, few studies offer a chance for present-day patients themselves to make these connections and narrate their own stories with regards to healthcare, without a narrowed focus analyzing the aftermath of specific well-known cases of medical abuse against Black individuals. Furthermore, outside of Thompson et al.'s 2022 study regarding Black women's reproductive care in the South,[32] scholarly treatment of the legacy of Southern antebellum medical logics in Black patients' experiences with medicine is limited to analyses of Jim Crow-era hospital

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[31] Simar Singh Bajaj & Fatima Cody Stanford, "Beyond Tuskegee - Vaccine Distrust and Everyday Racism," *New England Journal of Medicine* 384, no. 5 (2021): 2, https://dx.doi.org/10.1056/NEJMpv2035827.

[32] Terri-ann Monique Thompson et al., "Racism Runs through It," 195-202.

segregation.[33] [34] Additionally, studies and reports acknowledging the pervasiveness of racism in medical practice and experiments throughout U.S. history have seldom linked those to mistrust of the healthcare system within Black communities. Similarly, many studies on mistrust rightfully focus on individual experiences or fears of being ignored or the physician not making decisions in their best interest, but do not acknowledge those as a microcosm of a broader system enabling repeated abuses against Black patients throughout history, consequently perpetuating mistrust of medical professionals.

The research and theoretical framework in this thesis integrates the aforementioned scholarly treatments of medical wrongdoing and mistrust within Black communities to present a comprehensive inquiry into how the lasting legacies of medical conceptualizations of African American physiology *and* Black patients' unworthiness of receiving care from the antebellum era have informed both the way practitioners in the present day treat Black patients and the ability of Black patients to trust practitioners. Special attention will be given to experimentation on Black people, racism in medical training, and centuries of implicit (and explicit) biases from healthcare professionals. This project will further fill this gap in the scholarly literature by surveying Black patients regarding attitudes towards the healthcare field and healthcare providers, holding space for patients to make connections between historical events and their personal attitudes while honoring their decision to share as much or as little information regarding historical trauma as they wish.

Methodology

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[33] Lynn Marie Pohl, "Long Waits, Small Spaces, and Compassionate Care: Memories of Race and Medicine in a Mid-Twentieth-Century Southern Community," *Bulletin of the History of Medicine* 74, no. 1 (2000): 107-37, http://www.jstor.org/stable/44445345.

[34] Todd L. Savitt, "Walking the Color Line: Alonzo McClennan, the 'Hospital Herald,' and Segregated Medicine in Turn-of-the-Twentieth-Century Charleston, South Carolina." *The South Carolina Historical Magazine* 104, no. 4 (2003): 228-57, http://www.jstor.org/stable/27570652.

Much of the research presented in the forthcoming chapters concerning racial bias and mistreatment of Black patients before the modern era was conducted with the help of secondary literature, primary articles by antebellum scientists and doctors, and archival research with Woodruff Health Sciences Library's collections. Research presented on contemporary mistreatment and mistrust in the forthcoming chapters culminated findings from modern medical journals, personal narratives from various media types, and audiovisual content. This project is centered around the lasting implications of racist medical practice and attitudes fomented in the antebellum South, for medical trainees who ascribe to those ideologies and for Black communities with generations-deep mistrust of medical professionals for those reasons. To encapsulate the modern-day consequences of these parallel phenomena, Black adults based in the South were interviewed about their experiences with medical professionals. There was a foreseen limitation in patients of colors' comfort with sharing their experience, as the interviewer passed as white. To mitigate potential apprehension, questions were structured so patients would not feel compelled to reiterate traumatic experiences and their story was in their hands to tell. Furthermore, interviewees were given the option of whether or not to divulge their age, gender identity, or how they identify their racial or ethnic background. These anecdotal experiences were used to analyze the extent to which patterns of racism within the healthcare field continue from antebellum times, and to give a human voice to an issue often spoken about using only quantitative statistics.

Worth mentioning is that in this thesis, the definition of healthcare includes factors such as comfort, affordability, and access to facilities. These three factors will appear more when chronologically moving into the modern era and modern healthcare system, helping to emphasize the lasting impacts of exacerbating and causing pain in Black patients.

Chapter Outline

The first chapter of this thesis takes a trip through Southern United States medicine's fascination with the intentional, cruel affliction of Black pain for the pleasure of white researchers and physicians. Though many examples of such experimentation are documented throughout US history, the focus here is on how the crudeness of scientific racists during the antebellum period enabled later experiments targeting Black individuals with little to no scientific merit to take place.

Chapter two addresses how once hospitals became the primary venues of medical care across the United States, disparities in delivery of care and interactions with patients were more visible and better-documented. Such a trend in the medical field elucidated yet another trend: medical professionals deliberately neglecting to adequately address and treat Black patients' symptoms.

The third chapter uses interviews of Black adults based in the U.S. South to bring real experiences to a plethora of available statistics and scholarly analyses of medical racism. Interviewees' experiences with medical professionals and their ability to trust the medical field are contextualized in broader patterns of Black patients' experiences with being mistreated or intentionally dismissed by medical professionals in the South. This thesis concludes by arguing that medical mistrust, and the behaviors of medical practitioners which exacerbate it by ascribing to Southern antebellum medical logics, must be addressed and remedied.

Chapter 1

Intentional Production of Black Pain

This chapter will trace the ways that the acceptance of lower, cruder standards of dignity and care towards Black individuals enabled white medical professionals to utilize a Black person's body as an exhibit upon which to cruelly inflict pain rather than a body worth healing. First, the construction of Black people as more tolerant or fully incapable of feeling pain is linked to the transatlantic slave trade. The gruesome experiments of Dr. J. Marion Sims are then introduced as an example of both deliberate infliction of pain upon Black people and the perceived disposability of Black individuals' bodies, after which attention is given to enslaved Black womens' role as both co-producers of white medical practitioners' knowledge and as healers in their own right. Next, the phenomenon of disrespecting Black individuals' bodies as a systemic issue rather than the work of a handful of corrupted practitioners is articulated. The utilization of Black patients' pain for white scientists' accolades is then examined via the history of HeLa cells before drawing connections between Sims's experiments and a Columbia University study which intentionally harmed Black children, in addition to how the experiments of Sims and Columbia researchers echo the logics of antebellum scientific racist thought. Finally, the interim period between Sims's experiments and the Columbia study is analyzed as a period in which the same antebellum medical logics regularly surfaced in medical professionals' discourses and practices.

Colonial Origins

Assumptions of the Black body as one which is able to withstand or completely lack detection of pain date back to the colonial era, before the modern United States began to be colonized. During the early days of colonialism in the Caribbean and modern-day Latin America, European colonizers remained steadfast in their goal to conquer lands and peoples for the sole benefit of European interests. To achieve this goal, colonizers - most of whom were white males - had to construct fantastical myths about non-European societies and bodies to justify and rationalize their manufactured lower status. In her article titled "'Some Could Suckle over Their Shoulder': Male Travelers, Female Bodies, and the Gendering of Racial Ideology, 1500-1770," Jennifer Morgan writes, "Erroneous observations about African women's propensity for easy birth and breastfeeding reassured colonizers that these women could easily perform hard labor in the Americas while simultaneously erecting a barrier of difference between Africa and England."[35] She continues, "If African women gave birth without pain, they somehow sidestepped God's curse upon Eve. If they were not her descendants, they were not related to Europeans and could therefore be forced to labor on England's overseas plantations with impunity."[36] Such a mentality wrongly predicts Black women to have little pain during childbirth, a gateway to being deemed more suitable for physical labor. This is one of a plethora of justifications for slavery throughout the colonial era, requiring common society to be convinced that it wasn't so bad because Black people don't feel pain (even though this is far from the truth).

Colonizers conceived of now-disproven[37] myths that Black people can evade feelings of pain due to the large perceived need for labor in western colonies, for which a population had to be deemed enslavable and the irrefutable abuses they faced justified in order to gain popular support and personal agreement with the institution of slavery. If the belief that Black individuals cannot experience the intensity of pain that whites do is widely dispersed, along with any

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[35] Jennifer L. Morgan, "'Some Could Suckle over Their Shoulder': Male Travelers, Female Bodies, and the Gendering of Racial Ideology, 1500-1770," *The William and Mary Quarterly* 54, no. 1 (1997): 185, https://doi.org/10.2307/2953316.

[36] Morgan, "Some Could Suckle over Their Shoulder," 189.

[37] Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations," 4298.

convictions regarding the fecundity, intellect, or physiology of African-descended people, they enter into the realm of common knowledge and are unquestioningly employed to justify slavery. However, a falsehood is a falsehood, and the danger in such myths about pain and the Black body more generally is that when they enter spaces intended for healing, they effectively harm or fail to heal already-ailing Black individuals.

Betsey, Lucy, and Anarcha

In the introduction of this thesis, Annie Burton's recollection of seeing a lynching victim's corpse on display in a physician's office was presented. This lynching victim's fate as an experimental subject and spectacle provides an inroad to the reality many conscionable Black victims faced as well. The infamous 1840s case of Betsey, Anarcha, and Lucy is one such example. These three enslaved women were coerced into painful experimental operations by Dr. J. Marion Sims, eager to find a cure for vesicovaginal fistula, a common ailment among enslaved individuals in part due to early motherhood and lack of prenatal care.[38] Dr. Sims' personal accounts diminish the humanity of these young women by ignoring their pain. When describing the procedure he performed on Lucy in his autobiography, *The Story of my Life*, he explains, "That was before the days of anesthetics, and the poor girl, on her knees, bore the operation with great heroism and bravery."[39] He continues to describe in gory detail the number of times in which he had to go back and operate again after discovering flaws in his work, yet when considering the inevitable discomfort and trauma caused to Lucy, only commented, "Lucy's agony was extreme."[40] Despite these fleeting acknowledgements of his subjects' pain, he almost exclusively centers his own difficulties as the experimental surgeon rather than the subject on

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[38] Deirdre Cooper Owens, "The Birth Of American Gynecology," in *Medical Bondage: Race, Gender, and the Origins of American Gynecology* (Athens, GA: University of Georgia Press, 2017), 26, https://doi.org/10.2307/j.ctt1pwt69x.6.
[39] Sims, *The Story of My Life*, 237.
[40] Sims, *The Story of My Life*, 238.

which he undoubtedly inflicted extreme pain. The true depth of pain these women experienced during these invasive procedures is unknowable, however they suffered unimaginable agony and humiliation at the hands of Dr. Sims.

American medical professionals have demonstrated a tendency to seek knowledge and build their medical careers by deliberately producing pain in Black people. Some of the most scarring examples of Black people being forced to endure pain for white scientific gain hail from the context of medical experimentation such as Dr. Sims's experimentation on Betsey, Lucy, and Anarcha. Dr. Sims utilized his newly-learned technique to exclusively treat white women, and allowed the peering eyes of fellow physicians to observe his experimental procedures without the patients' consent. Though these women did have debilitating conditions, the means by which Dr. Sims provided care for them proved to be not with their benefit in mind, but rather with the ulterior motive of developing and refining a surgical technique. Owing to the crude nature of medicine in general during this era, it is notable that Dr. Sims performed more than 20 surgeries on each of these enslaved women, all without anesthesia, which *were* available during the 1840s despite Sims's rationale that they were not yet invented.

Additionally, Sims flatly admits in his autobiography, "I kept all these negroes at my own expense all the time,"[41] as he engaged in a process of trial and error on multiple patients prior to perfecting his technique. He speaks of the enslaved Black women forced to endure his experiments as though they are supplies to keep stock of rather than individuals in pain and in need of medical assistance. Taking a literary analysis approach to his autobiography reveals that he made this admission *after* his half-hearted acknowledgement of Lucy's pain, confirming his appeal to readers that any inkling of his guilt could be drowned out with a classic assertion by antebellum racists: Black peoples' bodies are disposable, and therefore their pain takes on a

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[41] Sims, *The Story of My Life*, 241.

diminished importance. It is safe to conclude that Dr. Sims had no intention of making the procedures comfortable for these women, either. He claimed that "if there was anything I hated, it was investigating the organs of the female pelvis."[42] Yet, he went forth with dozens of procedures in total on his three victims. An undesirable task warrants recruiting those also deemed undesirable. For Dr. Sims, this necessitated that his victims would be Black.

Sims's Victims as Co-Producers of Knowledge

The experiments on Betsey, Lucy, and Anarcha bolstered Sims's career and earned him both international recognition and the title, "Father of Gynecology."[43] Such a designation suggests that Sims himself was the primary producer of the knowledge he is credited with discovering, while failing to credit his victims' unwilling yet uncredited role as co-producers of that knowledge. In addition to the physical pain these women experienced from Sims, they have largely gone unappreciated by generations of medical professionals and scholars referring to Sims as the "Father of Gynecology" without acknowledgement of these womens' role in helping Sims improve his techniques. To qualify medical practitioners' and historians' seemingly instinctive recognition of Sims as the lone generator of knowledge within his work, Deirdre Cooper Owens enters the discourse on the implications of Sims's experiments in her book *Medical Bondage: The Birth of American Gynecology* with her assertion that:

> For pioneering gynecological surgeons, black women remained flesh-and-blood contradictions, vital to their research yet dispensable once their bodies and labor were no longer required. Neither Sims nor other early American physicians viewed Sims's slave patients as the maternal counterparts to Sims in his role as the "Father of American Gynecology."[44]

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[42] Sims, *The Story of My Life*, 231.

[43] Deirdre Cooper Owens, "Introduction: American Gynecology And Black Lives," *in Medical Bondage: Race, Gender, and the Origins of American Gynecology* (Augusta: University of Georgia Press, 2017), 1, https://doi.org/10.2307/j.ctt1pwt69x.5.

[44] Owens, "Introduction," 3.

It is important to recognize that “early American physicians”[45] is code for “white physicians” given the origin of Sims’s title in America’s antebellum period, directing attention to the racialized nature of medical practitioners’ praise of Sims and overlooking of his victims. Owens’s critique of white antebellum physicians’ utilization of Black patients as essential yet disposable brings to light the reality that Sims and white physicians more generally gleaned knowledge by inflicting suffering upon Black patients. Her argument emphasizes that Sims’s work would have been impossible without his victims being forced to yield their bodies to his experiments, so it is only fair that Sims himself not be considered to be the lone producer of knowledge and discoveries – his victims are as well. Therefore, reference to Sims as the “Father of Gynecology” erases his victims and misrepresents Sims as the sole architect of the knowledge he is credited for producing, while effectively dehumanizing his victims by failing to acknowledge their part in the work Sims continues to garner praise for.

Furthermore, designating Sims as the primary producer of gynecological knowledge vastly undermines the role enslaved Black women played not just in the discoveries made possible by forced experimentation on their bodies, but the broader role enslaved women had in healing. Owens argues:

> …black women, especially those who were enslaved, can arguably be called the “mothers” of this branch of medicine because of the medical roles they played as patients, plantation nurses, and midwives. Their bodies enabled the research that yielded the data for white doctors to write medical articles about gynecological illnesses, pharmacology, treatments, and cures.[46]

In essence, enslaved Black women already did much of the heavy lifting related to caring for individuals through pregnancy, childbirth, and various other illnesses for that matter, long before Sims gained recognition for his surgical techniques. This contention echoes that of scholars such

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[45] Owens, “Introduction,” 3.

[46] Deirdre Cooper Owens, “Chapter One: The Birth of American Gynecology,” in *Medical Bondage: Race, Gender, and the Origins of American Gynecology* (Augusta: University of Georgia Press, 2017), 25, https://doi.org/10.2307/j.ctt1pwt69x.5.

as Sharla Fett that Black women were trusted as healers and midwives in enslaved communities, with a wealth of herbal and spiritual knowledge guiding their practice.[47] Reliance on Black women for midwifery and other forms of healing practice draw, in part, upon enslaved Black communities' inability to trust white physicians.[48] Together, Owens presents an analysis complementary to Fett's, situating the responsibility of healing bestowed upon Black women as possessing a dualistic manifestation: Black women were recruited to administer remedies, and also forced to endure haphazard scientific experiments proclaimed as a means to improve white scientific knowledge and western medicine.

Henrietta Lacks

Even when pain is not actively produced by experimentation, existing pain in Black individuals may be capitalized upon by white physicians for scientific benefit. One notable example is that of Henrietta Lacks, a poor young Black mother who presented to Johns Hopkins hospital - one of the few treating poor Black patients at the time - in 1951. Her diagnosis of cervical cancer would prove fatal in a matter of months, but she quite literally lived on. Doctors discovered that her cancerous cells could survive outside of the human body, and without her or her family's consent, they were branded as "HeLa cells" and shipped to laboratories across the world for research and drug development.[49] A quick keyword search of "HeLa cells" on Web of Science or PubMed reveals upwards of 11,000 studies which have utilized her cells between 1953 and 2022, many without recognition of the patient the initial cell culture was covertly extracted from. Lacks did not experience any additional physical pain as a result of this unethical

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[47] Fett, "Spirit and Power," in *Working Cures*, 53-59.

[48] Fett, "Spirit and Power," in *Working Cures*, 33-35.

[49] Henrietta Lacks was diagnosed and treated at Johns Hopkins Hospital, which was built as a charity hospital in 1889. Many of its patients were unable to afford medical care, and many were Black. It was not uncommon for doctors to use patients in public hospitals such as Hopkins as clinical research subjects in exchange for their treatment. For more information, see Rebecca Skloot, *The Immortal Life of Henrietta Lacks* (New York: The Crown Publishing Group, 2010).

usage of her cells, but her existing pain and suffering were turned into profit by the white practitioners tasked with treating her. Though there is an ethical dilemma of whether this breach in patient rights was justified given the number of lives saved by discoveries enabled by HeLa cells, that is beyond the scope of this thesis.

After Sims

Between the years of J. Marion Sims's cruel experiments on Betsey, Lucy, and Anarcha, and the mid-to-late 20th century, researchers continued to use vulnerable Black individuals they wrote off as expendable for nontherapeutic, risky experiments. In the introduction to Harriet Washington's *Medical Apartheid*, several contributing factors to this recurrence are listed: physicians' ready discrediting of African American subjects' reports of abuses by researchers, restricting medical training programs to whites only, and a steady reliance on low Black literacy rates. Perhaps most tainting, however, is the disposability and devaluation of Black subjects' bodies in white researchers' eyes that Washington describes, as evidenced by a statement by a 1940s Public Health Service physician: "'The future of the Negro lies more in the research laboratory than in the schools…When diseased, he should be registered and forced to take treatment before he offers his diseased mind and body on the altar of academic and professional education.'"[50] Washington documents these attitudes and practices as present in documented research studies as late as 1995, when Clarence Lushbaugh, a radiation scientist, proclaimed that he "chose 'slum' patients as radiation subjects because 'these persons don't have any money and they're black and they're poorly washed.'"[51] Though this is just a sampling of cases, the parallels in attitudes classifying Black individuals' bodies as cheap, disposable, and consequently

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[50] Washington, "Introduction," in *Medical Apartheid* (New York: Doubleday, 2006), 10.
[51] Washington, "Introduction," 10-11.

undeserving of good health evidently show few signs of losing steam despite existing for several generations of medical professionals.

Columbia University & New York State Psychiatric Institute Fenfluramine Study

Despite the temporal gap of more than 100 years, there are many parallels between Dr. Sims's perception of Black pain tolerance and a study conducted during the 1990s by Columbia University in partnership with the New York State Psychiatric Institute, during which low-income African American and Hispanic (specifically, Black Dominican) children were recruited for a study analyzing whether the neurotransmitter serotonin was positively correlated with increased aggressiveness and a greater tendency to commit criminal activity.[52] Worth mentioning is that in addition to the Hispanic population recruited for this study - despite "Hispanic" being inclusive of multiple races including white - being deliberately recruited from a Black Dominican community, white children were explicitly prevented from joining the study, highlighting the racially-targeted nature of the researcher's investigations.

During the Columbia University study, children were administered fenfluramine, a drug known to increase serotonin levels. However, fenfluramine already gained a bad reputation for being part of the weight-loss drug Fen-Phen, from the 1970s to 1990s, leading to heart valve damage, brain damage, and death. Though the Columbia study began prior to fenfluramine's FDA ban in 1997, the drug's harmful effects were well-documented across medical literature by the early 1990s. Fenfluramine was always restricted to adult use, and 90% of adults experienced psychiatric, digestive, vision, and consciousness symptoms upon taking one dose of it. It may be argued that these harmful effects could have been accepted as a risk of study participation; however, good background research by the investigators would have come across the alarming

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[52] Washington, "The Children's Crusade," in *Medical Apartheid* (New York: Doubleday, 2006), 273.

risks associated with fenfluramine. Not to mention a critical flaw in the research plan: serotonin had already been widely disproven to have any impact on aggression. During the experiment, in addition to administration of the toxic drug, several participants were removed from life-saving medications for one month, and all had food and water withheld from them.[53]

One participant, Isaac Johnson, was six when recruited by Columbia University, with the glossy promise of $100 for his mother and a Toys-R-Us gift certificate for him contingent upon his enrollment in the study. The short term financial compensation pales in comparison to the long-term impacts of the drug that continued to haunt him as of his mother, Charisse Johnson's, 2006 Congressional testimony: headaches, hyperventilation, nightmares, and hallucinations. One can only guess the fallout for other participants.[54] Combined with the not-so-subtle intentions of only recruiting Black children, this study echoes a trend in clinical research that transcends generations: deliberate infliction of pain upon Black individuals for the advancement of a predominantly white healthcare profession.[55]

In addition to the severe physiological consequences of this study for its participants, there were major social ramifications which were telling of how the study's investigators viewed Black people, specifically Black families and children. When families were initially brought to Columbia's campus for preliminary interviews, according to Johnson, they were asked "'intimate, degrading questions'"[56] and researchers "took advantage of fears for the well-being of

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[53] Washington, "The Children's Crusade," 274a.
[54] Washington, "The Children's Crusade," 278.
[55] Washington provides an in-depth critique and walk-through of many cases in which white western medicine and *antebellum logics worked in concert to abuse Black patients and research subjects. Considering the weight and depth of the topi*c at hand, however, Washington's treatments are in no way comprehensive. For more information, see Dorothy E. Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Vintage Books, 2017); Dorothy E. Roberts, *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century* (New York: New Press, 2011).
[56] Washington, "The Children's Crusade," 274b.

[their children] to intrude on the privacy of [their] home.'"[57] Psychiatrists who saw these boys during these preliminary screenings also diagnosed them with a multitude of psychiatric disorders commonly ascribed to youth in the legal system, labeling them as mentally ill and making them vulnerable to the throes of both incarceration and institutionalization.[58] In these ways, Columbia researchers bought into and reinforced pervasive stereotypes that Black mothers are irresponsible parents[59] and Black boys are more prone to violent behaviors,[60] utilizing the research process to further stigmatize Black peoples' mere existence and satisfy white Americans' perceptions of Black families. Therefore, the harm done to the victims of the Columbia study lies not only in the bodily harm they sustained, but also in the weaponization of dangerously false stereotypes diminishing the humanity of Black people as justification for committing acts of harm through science.

The role of the Black body as an object to be experimented upon rather than therapeutically treated is enabled by a longstanding acceptability of creating Black pain for no benefit to those it is inflicted upon. Though the Columbia University fenfluramine study did not occur in the South, it is emblematic of the wide geographical and temporal reach of Southern antebellum conceptualizations of Black patients' disposability seen initially in cases such as Sims's procedures. In both Sims's experiments and the Columbia study, the racial dynamics between those conducting the study and those being experimented upon put the victims in a position of relative powerlessness - and the experimenters took advantage of this. Furthermore, the fenfluramine study participants were already vulnerable - as children - and were denied

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[57] Washington, "The Children's Crusade," 274c.
[58] Washington, "The Children's Crusade," 274d.
[59] Nicole Rousseau, "Social Rhetoric and the Construction of Black Motherhood," *Journal of Black Studies* 44, no. 5 (2013): 461-62, http://www.jstor.org/stable/24573096.
[60] Phillip A. Goff et. al., "The Essence of Innocence: Consequences of Dehumanizing Black Children," *Journal of Personality and Social Psychology* 106, no. 4 (2014): 530-32, https://dx.doi.org/10.1037/a0035663.

necessary medications and food. Researchers willingly put vulnerable individuals in danger and pain for supposed scientific benefit. The cruelty of this study is exacerbated by the knowledge that no such research was warranted in the first place: scientific literature has established no link between serotonin and aggression. The precedent of Southern antebellum medicine made this study evade red flags that would have prevented or seriously limited its ability to harm children.

Afterlife of Cartwright in Sims & Columbia Study

Experiments such as Sims's and the Columbia study echo the ghosts of scientific racists such as Samuel Cartwright, with the former's premise on Black individuals' perceived high pain tolerance and the latter's conceptions of aggression and disobedience as uniquely pathologized in Black people.[61] Cartwright was an antebellum physician known by scholars of slavery as a proponent of the institution,[62] as well as the hard labor and brutality accompanying it. In an 1851 article Cartwright wrote in the *New Orleans Medical and Surgical Journal*, he reported on the condition of "Dysaesthesia,"[63] known as "rascality"[64] to overseers, which was specific to Black people and characterized by mischievous and clumsy behaviors.[65] His article detailed an alleged remedy for the condition:

> The best means to stimulate the skin is, first, to have the patient well washed with warm

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[61] Samuel A. Cartwright, "Report on the Diseases and Physical Peculiarities of the Negro Race. New Orleans," *New Orleans Medical and Surgical Journal* 7 (July 1850-May 1851): 707-709, https://archive.org/details/neworleansmedica7185unse/page/708/mode/2up?view=theater.

[62] Cartwright presented a host of physiological and biblical justifications for slavery as the condition intended for Black people to be in. He was a major promoter of false ideas that Black people could not be overworked, were intellectually stunted in comparison to whites, and were fit to withstand brutal beatings and forced labor, further rationalizing the institution of slavery. For more information, see James Denny Guillory, "The Pro-Slavery Arguments of Dr. Samuel A. Cartwright," *Louisiana History: The Journal of the Louisiana Historical Association* 9, no. 3 (1968): 209–27, http://www.jstor.org/stable/4231017; Christopher D. E. Willoughby, "Running Away from Drapetomania: Samuel A. Cartwright, Medicine, and Race in the Antebellum South," *Journal of Southern History* 84, no. 3 (2018): 579-614, doi:10.1353/soh.2018.*0164; Samuel A. Cartwright, "Dr. Cartwright on the Caucasians and the Africans," DeBow's Review 25, no. 1 (1858): 45-56, https://quod.lib.umich.edu/m/moajrnl/acg1336.1-25.001/53:8?page=root;rgn=main;size=100;view=image.*

[63] Cartwright, "Diseases and Physical Peculiarities," 709.

[64] Guillory, "The Pro-Slavery Arguments," 215.

[65] Cartwright, "Diseases and Physical Peculiarities," 710.

> water and soap; then, to anoint it all over with oil, and to slap the oil in with a broad leather strap; then to put the patient to some hard kind of work in the open air and sunshine, that will compel him to expand his lungs, as chopping wood, splitting rails or sawing with the cross-cut or whip saw.[66]

In other words, Cartwright condoned whipping and the assignment of hard labor as a solution to enslaved Black people who were not diligent in their work. A similar logic of Black people having the intrinsic quality of pain tolerance was exercised in Sims's experiments. Cartwright anchors the antebellum scientific perception of Black people as naturally resistant to pain – such as whipping and forced physical labor – and thus innately suited for the demands of slavery, translated into Sims's experiments as the ability to withstand repeated crude surgeries without anesthetic. Both Cartwright's and Sims's attitudes towards Black people existed within the context of slavery, fortifying the logic that fitness for slavery was predicated on Blackness.

As for Cartwright's echoes in the Columbia study, despite the study occurring more than a century following the legal termination of slavery, his medicalizing of enslaved Black peoples' disobedience – "Dysaesthesia" – is mirrored in the Columbia researchers' pathologizing of aggression and impulsive behavior in Black youth. Given that Cartwright advocated for sentencing disobedient enslaved Black people to whippings and hard labor, it is noteworthy that Columbia researchers readily inflicted suffering – withholding food, water, and medication, while administering a drug known to produce harmful and deadly effects – upon Black children they preconceived as prone to disobedient behaviors. In this way, Cartwright's legacy was inherited by subsequent generations of American medical practitioners and researchers, enabling those complicit in the Columbia study to carry out their experiments with little regard for the pain and suffering – not to mention, the lifelong health consequences – they inflicted upon vulnerable youth of color.

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[66] Cartwright, "Diseases and Physical Peculiarities," 712.

A Systemic Issue

Racial power dynamics of the antebellum and Nadir eras – enslavement, the plantation system, and white supremacy – explain instances of white clinicians and researchers abusing Black patients' bodies, yet understandably make it challenging to rationalize the less common, but nonetheless significant, role of Black individuals in these egregious practices. The case of Grandison Harris is also particularly revealing about the demographic groups from which culprits of medical wrongdoings originated: Harris was a formerly enslaved African American man. Yet he was complicit in the infamous practice of "grave-robbing,"[67] providing benefit to the predominantly white institution of western medicine by digging up bodies from Black cemeteries without the consent of their families. Though one could come up with a host of justifications for not implicating him - he was enslaved, he was at the bottom of a strict racial hierarchy in the antebellum South, etc. - no circumstance can overwrite the interracial involvement in grave robbing and other medical and experimental abuses. Harris's story is in conflict with recent reports stating that among Black patients, doctor-patient racial concordance is associated with better health outcomes and greater trust placed in the doctor.[68] What findings like this confirm is that the institution of medicine as a whole - rather than just individual players - should be implicated for systemically ensuring worse health outcomes and abysmal treatment of Black patients, regardless of the racial identity of those who participate in it. American medicine allowed for lynching victims to become spectacles in physicians' offices, and for Black children to be given harmful doses of toxic therapeutics without parental consent - or parents' desperate financial situation and lack of scientific literacy being exploited by researchers.

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[67] Lane Allen, "Grandison Harris, Sr.: Slave, Resurrectionist, and Judge," *Bulletin of the Georgia Academy of Science* 34, no. 4 (1976): 194; Medical College of Georgia Faculty Meeting Minutes, January 5, 1852, Historical Collections & Archives, Robert B. Greenblatt Library, Augusta University, Augusta, GA.

[68] Marcella Alsan, Owen Garrick, and Grant Graziani, "Does Diversity Matter for Health? Experimental Evidence from Oakland," *American Economic Review* 109, no. 12 (2019): 4095, https://dx.doi.org/10.1257/aer.20181446.

Additional evidence implicating the American medical system at large rather than just a "handful of bad apples" in the medical field can be found in plantation narratives surrounding healing. Josephine Bacchus, a formerly enslaved woman interviewed by the Works Progress Administration in 1938, described a lack of trust of medical professionals on plantations but an abundance of treatments available by Black healers:

> Oh, de people never didn' put much faith to de doctors in dem days. Mostly, dey would use de herbs in de fields for dey medicine. Dere two herbs, I hear talk of. Dey was black snake root en Sampson snake root. Say, if a person never had a good appetite, dey would boil some of dat stuff en mix it wid a little whiskey en rock candy en dat would sho give dem a sharp appetite. See, it natural cause if you take a tablespoon of dat bitter medicine three times a day like a person tell you, it bound to swell your appetite. Yes, mam, I know dat a mighty good mixture.[69]

Bacchus never specifies that the doctors who saw her and others around her who were enslaved were white, but given that she is discussing her experiences in antebellum South Carolina, it is almost a sure bet that the mistrusted doctors were white. The use of inclusive language ("de people," "dey") refers to a collective memory within Bacchus's community positioning practitioners of western medicine as untrustworthy, and owing to the unquestionable power dynamic between a white interviewer and a formerly enslaved Black woman during the 1930s, her mention of this collective mistrust only emphasizes the weight of its importance in Southern Black communities. Furthermore, the plethora of remedies offered by Black healers on Southern plantations are indicative of a self-sustaining philosophy and approach to health and healing amongst enslaved Southern Black communities. Though many of these remedies hailed from traditions passed down through generations of Africans,[70] and were thus one way of resisting the cultural annihilation threatened by the institution of slavery, it is worth pondering whether their

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[69] Josephine Bacchus, Interview by Annie Ruth Davis, Marion, S.C, Born in Slavery: Slave Narratives from the Federal Writers' Project Works Progress Administration, Federal Writers' Project, January 4, 1938, Library of Congress.

[70] Sharla M. Fett, "Doctoring Women," in *Working Cures: Healing, Health, and Power on Southern Slave Plantations* (Chapel Hill, NC: UNC Press, 2002), 130-1.

continued necessity on the plantation followed an inability to trust one's health in the hands of white slave doctors.[71]

Chapter Summary

To understand the origins of dismissal of Black patients' pain, attention must be given to the aforementioned denials that Black individuals are capable of feeling pain. This assertion by many antebellum scientists and physicians, and by many medical students today,[72] is completely nonsensical and scientifically unproven. Pain is the body's response to danger or illness, an alert that something is not right. When Black patients' pain is ignored, by extension underlying health issues go undetected and ignored by healthcare professionals, ultimately worsening one's health outcomes and prognosis.[73] This interplays with Black patients' experiences with healthcare in two important ways. One, the presumption that Black individuals are better able to withstand cruel medical experimentation due to lack of pain sensation is used to justify such experiments. Second, if healthcare professionals take the myth of absence of Black pain to heart, they can perpetually justify limiting quality and depth of care to Black patients with the assertion that they do not feel pain and must therefore be "exaggerating" complaints. The proceeding chapter will delve into the latter argument, focusing on both institutional- and individual-level ways in which Black patients' healthcare needs are intentionally neglected.

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[71] Fett, "Sacred Plants," in *Working Cures*, 67-8.

[72] Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations," 4298.

[73] Mansella et al., "Delayed Diagnosis," 589-97; Jasmine M. Miller-Kleinhenz et al., "Racial Disparities in Diagnostic Delay among Women with Breast Cancer," J*ournal of the American College of Radiology* 18, no. 10 (2021): 1384-93, https://dx.doi.org/10.1016/j.jacr.2021.06.019; Ronald M. Witteles et al., "Screening for Transthyretin Amyloid Cardiomyopathy in Everyday Practice," *JACC: Heart Failure* 7, no. 8 (2019): 711, https://dx.doi.org/10.1016/j.jchf.2019.04.010.

Chapter 2

Denial of Care

Post-Emancipation Era & Hospital Movement

Dr. Vanessa Northington Gamble classifies the Black Hospital Movement as the time between the mid-1800s and the 1920s, a historical moment in which African American communities sought to establish their own healthcare facilities in response to segregation and white medical facilities' denial of services to Black patients.[74] This period marked a critical point when the healthcare needs of African Americans were being addressed at a national level, marked by the opening of the Freedmen's Bureau-sponsored hospitals in the Reconstruction South. For example, in Alabama alone, 3 hospitals for freedmen were opened by the end of 1865 to meet the needs of now-emancipated African Americans who understandably had significant healthcare needs.[75] As the beacon of the antebellum medical logics weaponized against Black patients and home to several key medical journals up until this point, this was a surprising turn for the South, a region reliant on slavery and the maintenance - not health - of Black people to sustain its economy. Yet, it is crucial to acknowledge that Bureau programs including hospital construction were commenced by an act of Congress, not by Southern policymakers or medical professionals.

However, with the termination of Freedmen's Bureau programs in the 1870s came the loss of federally-funded healthcare programs for African Americans. As the time period known as the Nadir commenced and antipathy regarding African American freedoms and rights increased, so too did a medical phenomenon reminiscent of the antebellum era: deliberate lack of

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[74] The Black Hospital Movement, while arguably beginning in charitable white Southerners' projects to build hospitals for enslaved people, is best known for Vanessa Northington Gamble, *Making a Place for Ourselves: The Black Hospital Movement, 1920-1945* (New York: Oxford University Press USA, 1995).

[75] Elizabeth Bethel, "The Freedmen's Bureau in Alabama," *The Journal of Southern History* 14, no. 1 (1948): 60, https://doi.org/10.2307/2197710.

concern for Black suffering. The previous chapter assessed American medicine with producing and enabling Black pain, a mythical antebellum holdover still commonly believed among healthcare professionals and trainees. Though the denial that such pain could be felt is a major aspect of enabling and deliberately causing it, the advent of the hospital movement means that researchers should give special attention to the dismissal of Black pain and illness, including intentionally lower-quality treatment and utilizing treatment as a front for experimental purposes. The hospital, once a "welfare institution that cared for…indigent and dependent persons"[76] which "offered no therapeutic advantages over domestic care"[77] became a symbol of healing rather than death around the turn of the 20th century.[78] This meant that despite segregation and institutionalized racism, there *were* more therapeutic avenues available for Black individuals in need of medical treatment, and thus more opportunities for healthcare professionals to heal Black patients. Because the means now existed to relieve and cure more ailments, attention should be given to groups who white medical practitioners denied or reluctantly offered these potentially life-saving therapeutics to.[79] With the Supreme Court's 1896 decision in *Plessy v. Ferguson* that the establishment of "equal but separate accommodations for the white, and colored races"[80] was not a Constitutional violation, segregation became a mainstay of everyday life for African Americans, including within medicine. As a result of institutionalized segregation enabled by *Plessy*, there were disproportionately few facilities at which Black patients could receive medical

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[76] Gamble, "Roots," in *Making a Place*, 4a.

[77] Gamble, "Roots," in *Making a Place*, 4b.

[78] Norma B. Erickson, "African-American Hospitals and Health Care in Early Twentieth Century Indianapolis, Indiana, 1894-1917" (Master's Thesis, Indiana University, 2016), 8-9.

[79] For over 100 years, from the 1870s to the 1980s, the American Medical Association effectively excluded African American physicians via their denial of admission to the integrated National Medical Society and acceptance of various reports justifying the exclusion of either African American physicians or Black medical societies. For more information, see Robert B. Baker, "The American Medical Association and Race," *Virtual Mentor* 16, no. 6 (2014): 479-488. doi: 10.1001/virtualmentor.2014.16.6.mhst1-1406; Robert B. Baker et al., "Creating a Segregated Medical Profession: African American Physicians and Organized Medicine, 1846-1910," *Journal of the National Medical Association* 101, no. 6 (2009): 501-12, https://dx.doi.org/https://doi.org/10.1016/S0027-9684(15)30935-4.

[80] Plessy v. Ferguson, 163 US 537 (1896).

care throughout the United States, while many health authorities displayed apathy towards the needs of Black communities.[81] This is where the focus of this thesis shifts to Black patients from the 1890s onwards and doctors' dismissal of their pain, suffering, and concerns about potentially serious health conditions. This chapter will discuss various ways in which the intentional neglect of Black patients' concerns by healthcare professionals was increasingly obvious following the end of slavery, relying on stereotypes and medical logics from the antebellum period and leading to distrust in the healing capabilities of modern medicine.

Limits placed on Black health by the US healthcare system extend back to the transatlantic slave trade era, in which maintenance of laboring capacity rather than physical health of Black individuals was prioritized by enslavers.[82] Black patients' bodies were defined as entities not meant to be healed, but rather to be utilized for others' (in this case, whites') benefit. Once the era of forced labor formally ended and institutionalized segregation was written into law, it became permissible for Black patients to receive medical treatment in standard healthcare facilities, albeit poor quality treatment at best.[83] As demonstrated by antebellum examples such as J. Marion Sims's crude experimental treatments on enslaved women, Southern medicine had established acceptance of providing lower quality treatment to Black patients than to white patients. Ironically, especially after considering Sims's procedures specifically, this norm gave white medical practitioners a pass to deny agony felt by Black patients as a result of their condition or due to a treatment they received. Some critics argue that Sims's victims were actually receiving medical care,[84] so this case cannot be compared with those of physicians

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[81] Paul B. Cornely, "Segregation and Discrimination in Medical Care in the United States," *American Journal of Public Health* 46, no. 9 (1956): 1074-75, https://dx.doi.org/10.2105/ajph.46.9.1074; Skloot, "The Exam," in *The Immortal Life of Henrietta Lacks* (New York: The Crown Publishing Group, 2010).

[82] Stephanie E. Smallwood, *Saltwater Slavery: A Middle Passage from Africa to American Diaspora* (Cambridge: Harvard University Press, 2008), 43-44.

[83] Gamble, "Under the Shadow," 1774-75b.

[84] L. Lewis Wall, "The Medical Ethics of Dr J Marion Sims: A Fresh Look at the Historical Record," *Journal of Medical Ethics* 32, no. 6 (2006): 346-50, https://dx.doi.org/10.1136/jme.2005.012559; Sara Spettel and

blatantly refusing to care for, or acknowledge the symptoms of, Black individuals. The victims of Sims would have many Black patients and research subjects follow in their footsteps, revealing a disturbing trend in American medicine: refusing to see ailing Black individuals as what they are – people in pain – not experimental subjects or chronic exaggerators.

Segregation as Refusal to Address Black Patients' Healthcare Needs

Practices of segregation and refusal (or limitation) of treatment and healthcare facilities to Black patients hinge upon the objective of dismissing Black individuals' health concerns and sending the message that Black people are unworthy of receiving high-quality medical care. Such realizations provoked Dr. Alonzo McClennan, an African American physician based in Charleston, South Carolina, in the 1890s. In the midst of an increase in violence towards African Americans during this time of increasingly strict segregationist policies, he brought several concerns regarding Black health to the limelight: the lack of facilities at which Black patients could receive quality (or any) healthcare, the lack of training facilities for Black doctors and nurses, and the lack of medical literature concerning Black patients and physicians.[85]

During the era of segregation, even when white physicians *did* see Black patients, the quality of care and respect for the patient was minimal. One such example comes from Chalmers Archer, Jr., who cites the case of a Black mother in labor during his time as a young man in 1930s Mississippi as justification for his disdain for white physicians. The mother he mentions had a white physician called to attend her difficult labor, and after her husband asked the doctor to drive them to the hospital - following the doctor's instruction to go to the hospital - he refused and left the mother without medical supervision. Hearing about this incident spawned his

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Mark Donald White, "The Portrayal of J. Marion Sims' Controversial Surgical Legacy," *Journal of Urology* 185, no. 6 (2011): 2424-27, https://dx.doi.org/doi:10.1016/j.juro.2011.01.077.

[85] Todd L. Savitt, "Walking the Color Line: Alonzo McClennan, the 'Hospital Herald,' and Segregated Medicine in Turn-of-the-Twentieth-Century Charleston, South Carolina," *The South Carolina Historical Magazine* 104, no. 4 (2003): 230-31, http://www.jstor.org/stable/27570652.

hesitancy to seek care from southern white physicians unless absolutely necessary due to the frequency of white physicians denying treatment to Black patients like this mother in labor.[86] This is a case in which a physician was well aware of the medical issue at hand and had the knowledge to help the patient. Despite the necessary action by the physician being nonclinical (a ride to the hospital) rather than a medical intervention, Archer's testimony follows trends in which physicians knowingly exacerbate pain or health concerns, failing to intervene as necessary to ensure the best outcome for the patient.

From this anecdote, two continuations into the present day can be recognized. First, the context of this mother's peril surrounding maternal health deserves greater attention, as maternal and fetal health concerns can be life-or-death situations. In recent years, there has been much conversation surrounding the fact that, despite notions of living in a "post-racial" society where segregation is outlawed, Black women are *still* 2 to 6 times more likely than white women to die in childbirth.[87] Though studies concluding this vast disparity in maternal mortality vary in the reasons they found for these statistics – greater likelihood of cardiac disease,[88] hemorrhage,[89] and hypertension[90] – the story Archer tells and others like it beg the question of whether physicians are ignoring warning signs in Black maternal patients at a greater rate. The truth is, Black people giving birth raise alarms about potentially life-threatening symptoms, ruling out blame or lack of

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[86] Chalmers Archer, Jr., *Growing Up Black in Rural Mississippi: Memories of a Family, Heritage of a Place* (New York: Walker, 1992), 89; Lynn Marie Pohl, "Long Waits, Small Spaces, and Compassionate Care: Memories of Race and Medicine in a Mid-Twentieth-Century Southern Community," *Bulletin of the History of Medicine* 74, no. 1 (2000): 117, https://www.jstor.org/stable/44445345.

[87] Mary Beth Flanders-Stepans, "Alarming Racial Differences in Maternal Mortality," *The Journal of Perinatal Education* 9, no. 2 (2000): 50, https://dx.doi.org/10.1624/105812400X87653. For more information on how American medicine has failed Black women, see Dorothy E. Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Vintage Books, 2017).

[88] Emily E. Petersen et al., "Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017," *MMWR Morbidity Mortality Weekly Report* 68, no. 18 (2019): 423–429. DOI: http://dx.doi.org/10.15585/mmwr.mm6818e1.

[89] Petersen et al., "Vital Signs," 424.

[90] Margaret A. Harper et al., "Racial Disparity in Pregnancy-Related Mortality Following a Live Birth Outcome," *Annals of Epidemiology* 14, no. 4 (2004): 278, https://dx.doi.org/https://doi.org/10.1016/S1047-2797(03)00128-5.

decision-making ability regarding one's own body on the patient's behalf, but these concerns often fall on physicians' deaf ears.

Second, even for individuals who do not have the ability to get pregnant, such stories reinforce mistrust in medicine, as Archer reports of himself. If doctors refuse to ensure a safe and comfortable delivery for somebody about to bring a new life into the world, how can somebody be sure they will do no harm for somebody else in a less precarious position? Much of medicine involves avoiding health problems based on risk level, and early diagnosis and treatment when health issues do arise,[91] circling back to the alarmingly high rates of mortality among Black people giving birth. When urgent situations such as hemorrhaging are ignored, it logically follows that a physician would ignore seemingly less-urgent symptoms, practically diminishing the chances of having early detection and treatment to zero.

Struggles in Desegregating Medicine & Lead-Up to Civil Rights Movement

Up until the Civil Rights era, healthcare remained a far reach from Black communities. In response, Congress passed the Hill-Burton Act of 1946 to provide relief namely for Black communities in the South among which access to healthcare was scarcest in the nation. As part of the United States' postwar expansion era, Hill-Burton brought hospitals and healthcare investments to areas in southern states that were predominantly Black and had few hospitals, let alone ones which were accredited and sufficiently equipped to provide high-quality care.[92] Karen Kruse Thomas, a historian of medicine, emphasizes this was the first federal program which

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[91] Miller-Kleinhenz et al., "Diagnostic Delay," 1391; Laurie McGinley, "ACA Linked to Reduced Racial Disparities, Earlier Diagnosis and Treatment in Cancer Care," *Washington Post*, June 2, 2019, https://www.washingtonpost.com/health/2019/06/02/aca-linked-reduced-racial-disparities-earlier-diagnosis-treatment-cancer-care/.

[92] Karen Kruse Thomas, "The Hill-Burton Act and Civil Rights: Expanding Hospital Care for Black Southerners, 1939-1960," *The Journal of Southern History* 72, no. 4 (2006): 825–27, https://doi.org/10.2307/27649234.

guaranteed "racial parity"[93] in allocation of funds. However, the legacy of Hill-Burton proved that desegregation and racism built into healthcare access would be a marathon rather than a sprint. Despite the act allocating funding for the construction of biracial hospitals, the act itself contained a separate-but-equal clause, effectively upholding segregated healthcare in the areas it targeted.[94] Thompson argues that legislation calling for desegregation in the 1940s would have likely caused it to die, as had been the fate of other healthcare measures with otherwise vast support.[95] Clearly, desegregation of medical facilities remained a contentious issue in postwar debates on healthcare, a sign that recognition by the government that separate is inherently unequal would remain an uphill battle.

Continuing into the era of the Civil Rights Movement, the Supreme Court's decision in *Brown v. Board of Education* that segregation is unconstitutional[96] and the passage of the Civil Rights Act of 1964 prohibiting "discrimination in public accommodations and federally funded programs"[97] marked a shift in national attitudes towards segregation. Yet within the medical field, there were still drastically different conditions in Black and white medical facilities. In 1966, in the midst of politically-heated debates about whether to desegregate Alabama's psychiatric hospitals, the Office of Equal Health Opportunity at the federal level sent investigators into the state. In addition to noticing a dearth of medical practitioners, let alone those who were licensed, Dr. Kylie Smith reveals some of the disturbing findings in segregated children's psychiatric facilities, as described by a federal investigator sent to the scene:

'We went into the day room of one ward of black patients who were profoundly mentally

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[93] Thomas, "Hill-Burton," 839.
[94] Thomas, "Hill-Burton," 836.
[95] Thomas, "Hill-Burton," 834-36.
[96] Brown v. Board of Education, 347 US 483 (1954).
[97] "Legal Highlight: The Civil Rights Act of 1964," Office of the Assistant Secretary for Administration & Management, U.S. Department of Labor, accessed April 10, 2022. https://www.dol.gov/agencies/oasam/civil-rights-center/statutes/civil-rights-act-of-1964#:~:text=The%20Act%20prohibited%20discrimination%20in,continues%20to%20resonate%20in%20America.

> retarded, with physical handicaps as well; many of them were sitting and/or lying on the floor in their own excrement. . . . [T]here was no ward for white profoundly retarded to match the depth of despair and mistreatment as this one for blacks.' Rose's observations demonstrate that "separate but equal" was never a reality in psychiatric facilities. Instead, the practice had created a space where people could be removed from visibility entirely and where Black patients existed in a complete vacuum of approaches to treatment or care.[98]

It cannot be stressed enough that the central tenant to "separate but equal" is that designated Black facilities - from restrooms to hospitals - were consistently subpar. When it comes to healthcare facilities, such as Alabama's psychiatric hospitals, a systematic unwillingness to apply high standards of care for Black individuals is blatant, and along with it a refusal to address and treat the medical concerns Black patients have.

Segregation of medical facilities bolstered justifications for providing Black patients lower quality healthcare than their white counterparts, an unhelpful pattern for a population already skeptical of the healing capacities of Western medicine. It is worth emphasizing that segregation of medical facilities was justified with ideas produced by antebellum medical practitioners that Black individuals are unintelligent and prone to deviance,[99] concepts which bolstered notions during the 1960s that Black people presented a danger to white populations.[100] These perceptions persisted due to the demonization they invite against Black individuals, which ultimately reduces them to subhuman and thus undeserving of the standards of care afforded to white populations. Despite segregation ending at various institutional levels beginning in the 1950s, we continue to see the same segregation-provoked refusal to treat Black patients or address their symptoms well into the present day. From here, a conversation opens into the continuation of healthcare professionals dismissing Black patients' concerns, culminating in a critical look into the Black community's mistrust of physicians.

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[98] Kylie M. Smith, "No Medical Justification: Segregation and Civil Rights in Alabama's Psychiatric Hospitals, 1952–1972," *Journal of Southern History* 87, no. 4 (2021): 664, doi:10.1353/soh.2021.0122.
[99] Smith, "No Medical Justification," 646-47.
[100] Smith, "No Medical Justification," 655-56.

Post-Segregation Era & Continued Neglect of Black Patients' Health

A common point of discussion in conversations surrounding health disparities is the disproportionate incidence of many chronic illnesses, combined with a relatively lower rate of screening and early diagnosis, in Black communities. Though the exact reasons may vary from lack of access to quality facilities to outright dismissal or intentional non-detection of symptoms, the latter must be considered as potentially exacerbating the former. For example, a 2021 study reports that Black women experienced a total delay - defined as the time between imaging (mammogram) and biopsy upon discovery of abnormal results - of 42 days on average, while their white counterparts waited on average 26 days between their mammogram and receiving a biopsy.[101] Even if physician antipathy is not cited as a contributing factor, one must question whether it is a factor in increased total delay of breast cancer biopsies in Black women, especially given the data and anecdotal evidence citing physicians' tendency to not listen to Black patients and the life-threatening circumstances of many Black birthing individuals.

Some may argue that Black patients' relatively lower levels of health insurance, environmental exposure, and socioeconomic disadvantage compared to white Americans are greater risk factors than physicians' dismissal of Black patients' symptoms and thus deserve more weight in conversations about health disparities. These are not negligible, as access to healthcare and environmental or community health risks are systemic issues that must be addressed with immediacy. However, though they may seem detached from the central theme of neglecting Black patients' healthcare needs and concerns, systemic injustices leaving Black patients disproportionately underinsured,[102] with greater exposure to environmental hazards,[103]

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[101] Miller-Kleinhenz et al., "Diagnostic Delay," 1386.

[102] Samantha Artiga et al., "Health coverage by Race and ethnicity, 2010-2019," *KFF*, July 16, 2021, https://www.kff.org/racial-equity-and-health-policy/issue-brief/health-coverage-by-race-and-ethnicity/.

[103] Renee N. Salas, "Environmental Racism and Climate Change – Missed Diagnoses," *New England Journal of Medicine* 385, no. 11 (2021): 967-69. https://dx.doi.org/10.1056/NEJMp2109160.

and more likely to live in poverty[104] *are* an institutional middle finger to the health of Black communities. Additionally, the consequences of physicians' deliberate neglect of Black patients' health concerns tacked onto the aforementioned limitations on Black healthcare access and general wellbeing, are presumably much deadlier. If a patient can finally visit a doctor regarding a lump or other concerning symptoms only to get dismissed, how great are their chances of getting an appropriate and timely diagnosis? And, in addition, will they *trust* medical practitioners to have their best interests in mind?

Here, the example of Tressie Cottom, a Black woman who wrote about her humiliating experience dealing with a pregnancy-related emergency, is instructive. She writes in a chapter titled "Dying to be Competent" from her book, *Thick: And Other Essays*, that she selected an OB/GYN in a whiter area of town due to her awareness of societal perceptions that white-serving medical facilities are of higher quality than those which are not. In her own words, "For many people I am sure that the medical practice was actually good. The happy, normal, thin white women in the waiting room every time I visited seemed pleased enough."[105] She admits that there was some degree of truth to her perception that this doctor's office provided quality medical care, yet qualifies this statement as applicable to a privileged demographic of patients: those who are thin and white. However, the quality of care she predicted she would receive from that office proved to only be available to that group of patients. When she started bleeding long before her expected due date, she was treated poorly by that same office:

> After I had bled through the nice chair in the waiting room, I told my husband to ask them again if perhaps I could be moved to a more private area to wait. The nurse looked alarmed, about the chair, and eventually ushered me back. When the doctor arrived, he

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[104] John Creamer, "Inequalities persist despite decline in poverty for all major race and Hispanic origin groups," *U.S. Census Bureau*, March 21, 2022, https://www.census.gov/library/stories/2020/09/poverty-rates-for-blacks-and-hispanics-reached-historic-lows-in-2019.html#:~:text=In%202019%2C%20the%20share%20of,share%20in%20the%20general%20population.

[105] Cottom, "Dying to Be Competent," 82.

> explained that I was probably just too fat and that spotting was normal and he sent me home…Finally, I called the nurse. She asked me if my back hurt. I said no…[i]t was my butt that hurt…[b]y the end of three days…I had not slept more than fifteen minutes straight in almost seventy hours.[106]

For one, Cottom's logic that seeking medical attention from an OB/GYN in a wealthier, whiter community would result in better outcomes is not unfounded. A study from 2014 in the *American Journal of Obstetrics and Gynecology* reveals that Black-serving hospitals report higher rates of delivery-related indicators, or complications related to a delivery, than white-serving hospitals, such as infections, birth-related embolisms, and emergency hysterectomies. At white- and Hispanic-serving hospitals, non-Hispanic Black patients were reported to have between 1.15 and 3.27 times greater risks of delivery-related indicators.[107] This study defined a hospital as serving a certain racial demographic if more than 50% of deliveries at that hospital were to patients of a single racial group (for example, at Black-serving hospitals, more than 50% of deliveries are to Black patients).[108] Here we see disparities in the quality of care both available to, and given to, Black individuals who are pregnant or delivering. The data that Black-serving hospitals perform more poorly than other hospitals when looking at delivery-related indicators of all patients at these hospitals - regardless of race - suggests that a lower quality of care is *accessible to* Black communities. Moreover, the poorer outcomes for Black individuals delivering at non-Black serving hospitals reinforces the findings of Flanders-Stepans,[109] Petersen et al.,[110] and Harper et al.,[111] that childbirth for Black individuals carries significantly greater risks than for white individuals.

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[106] Cottom, "Dying to Be Competent," 83.
[107] Andreea A. Creanga et. al., "Performance of Racial and Ethnic Minority-Serving Hospitals on Delivery-Related Indicators," *American Journal of Obstetrics and Gynecology* 211, no. 6 (2014): 647.e1.
[108] Creanga, "Performance," 647.e2.
[109] Flanders-Stepans, "Alarming," 50.
[110] Petersen, "Vital Signs," 423-429.
[111] Harper, "Racial Disparity," 278.

Though these studies focus on delivery rather than prenatal care, they can be contextualized with Cottom's story because labor and delivery are far more precarious situations for the individual who is pregnant than earlier stages in pregnancy. According to the World Health Organization, 75% of deaths related to pregnancy or childbirth outside of unsafe abortion are bleeding, infections, eclampsia, and delivery complications – all most common during or immediately after childbirth.[112] Though Cottom's situation meant the death of her fetus rather than the person who was pregnant, the operative in both cases is Black individuals who are carrying a child. With this in mind, the same assertion can be made as previously mentioned after introducing the story of Chalmers Archer, Jr.: if medical practitioners are unwilling to care for individuals during a high-risk event, they cannot be trusted to care for patients in less-dire situations. Regardless of the medical facility or area of town Tressie Cottom sought prenatal care at, her pregnancy and her health were automatically at a greater risk because she is Black.

Mistrust Through Generations

Word of physicians' unwillingness to help Black patients travels quickly and transcends generations, important considerations when analyzing perpetuated mistrust in the medical system in both the pre- and post-segregation eras of American medical history. Similar mistrust of white physicians was cited in a report by sociologist Jerome D. Frank, titled "Adjustment Problems of the Negro Soldier," in 1947. Frank's report surveyed 21 Black soldiers, at least seven of whom were born or located in the South. The overrepresentation of participants from the North and West, Frank contends, is likely due to greater economic opportunities there than in the South, since only middle- or upper-class Black soldiers were recruited. From the start of these interactions, Frank reported something not as explicit that speaks strongly to issues of mistrust:

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[112] "Maternal Mortality," World Health Organization, last modified September 19, 2019, https://www.who.int/news-room/fact-sheets/detail/maternal-mortality.

he reported that “Almost all patients displayed an initial uneasiness and reserve in the interview situation. This seemed directly related to the fact that the patient was colored and the physician white.”[113] Though Frank goes on to vindicate any of the interviewing physicians’ biases as causing this apprehension amongst the Black soldiers, he suggests that the “general background of inter-racial relationships”[114] was responsible for the interviewees’ uneasiness with the white physicians interviewing them. Frank further identifies Black soldiers’ “expectancy that his complaints would not be taken seriously”[115] as contributors to their mistrust. He cites the Army’s presumption that Black soldiers are assumed more than their white counterparts to report symptoms with ulterior motives of evading their duties, as central to this mistrust. Despite the somewhat outdated and problematic nature of this report, the familiar contention that Black patients are exaggerating or trying to invent a medical problem that does not exist understandably diminishes their ability to trust their health in white practitioners’ hands. Instead of vouching for laziness on behalf of Black patients, Frank’s report illuminates the recurring undertones that Black patients are simply unworthy of receiving care, causing white medical professionals’ unwillingness to thoroughly examine and treat them.

Another prime example of how entrenched mistrust is in African American communities comes from the notorious Tuskegee Syphilis Study, carried out by the US government between 1932 and 1972, before backlash and ethical concerns shut it down.[116] Originally titled “The Tuskegee Study of Untreated Syphilis in the Negro Male,” the study recruited 600 Black men–399 of whom had syphilis– and intentionally denied treatment to those who were

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[113] Jerome D. Frank, “Adjustment Problems of Selected Negro Soldiers,” *The Journal of Nervous and Mental Disease* 105, no. 6 (1947), 648.
[114] Frank, “Adjustment Problems,” 648.
[115] Frank, “Adjustment Problems,” 649.
[116] Gamble, “Under the Shadow,” 1773.

syphilitic.[117] Once the horrors of the Tuskegee study were brought to national attention, it became known that a huge breach in ethics was still possible even when conducted by the most prestigious research institutions in the world. A 2015 series of focus groups of African American adults divulged several accounts of mistrust directly attributed to Tuskegee, such as one respondent who remarked about suspicion towards the government, “You don’t know what they are giving you and what they’re experimenting on you. They are very secretive. They say one thing and might do another.”[118] This individual’s doubts that human subjects research in a clinical setting hold true to their descriptions on paper are telling of the clandestine nature of the Tuskegee study and the resulting catastrophic breach in already-fragile trust of medical institutions amongst African Americans. It also echoes other previously mentioned narratives, such as those of Annie Burton and Josephine Bacchus. This is no coincidence. The same government and medical institutions that, for a variety of aforementioned reasons, drove enslaved individuals to distrust western medicine, recycled its antebellum-era low standards for caring for Black patients, all the while planting the seeds of mistrust for white physicians in the Black community. Worth mentioning is that this experiment spanned the time before and after significant steps were taken to desegregate public spaces, so it refutes the argument that desegregation alone was the solution to Black patients’ ability to have their healthcare needs met, as segregation was non-operative in this study. Tuskegee’s scars have yet to heal among Black Americans, as proven by the number of Black Americans who directly attribute their medical mistrust to that study.

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[117] “The Tuskegee Timeline,” The U.S. Public Health Service Syphilis Study at Tuskegee, Centers for Disease Control and Prevention, last modified April 12, 2021, https://www.cdc.gov/tuskegee/timeline.htm.

[118] Darcell P. Scharff et al., "More Than Tuskegee: Understanding Mistrust About Research Participation," *Journal of Health Care for the Poor and Underserved* 21, no. 3 (2010): 886, https://dx.doi.org/10.1353/hpu.0.0323.

A telltale lasting sign that white-dominated healthcare professions have poor reputations in Black communities is Black individuals' relative comfort and trust of Black physicians and Black-run medical facilities.[119] Racial concordance between patients and physicians is higher for Black patients than for any other racial demographic: while 5% of physicians in the United States are Black, 23% of Black patients identify their primary care physician as also being Black.[120] Aside from researchers' hypotheses that this trend exists due to greater respect and familiarity with Black culture among Black physicians than white physicians, racially-concordant physician-patient pairings result in greater likelihood of Black patients opting to receive screenings for diseases such as cholesterol and diabetes when seen by a Black physician as opposed to a white physician.[121] This corroborates Dr. Alonzo McClennan's declarations from more than a century ago, that a greater presence of Black doctors in the medical field can at least partially improve healthcare access and quality for Black patients.

One important note is that though individual accounts of mistrusting doctors have existed for well over a century - Annie Burton, Chalmers Archer, Jr., and other medical narratives - the research and medical communities only began significantly honing in on medical mistrust as a larger-scale phenomenon in the post-Tuskegee era (starting in the 1980s). Though there was an incontestable shift in national conversations surrounding racism and attitudes towards diversity over the course of the 20th century which coincided with increasing clinical attention to racism, it should be emphasized that the "always trust the doctor" mentality remained prevalent in American medicine until later in the 20th century. Doctors were granted near-complete control over a patient's healthcare, and patients were afforded alarmingly little power in decisions

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[119] Gamble, "Under the Shadow," 1774-75c.

[120] Somnath Saha et al., "Patient-Physician Racial Concordance and the Perceived Quality and Use of Health Care," *Archives of Internal Medicine* 159, no. 9 (1999): 1000, https://dx.doi.org/10.1001/archinte.159.9.997.

[121] Alsan, Garrick, and Graziani, "Does Diversity Matter?", 4075.

regarding treatment and even knowledge that they have a terminal illness.[122] It is no surprise that this convention, on top of pervasive racism and structural barriers facing African Americans, prevented many from reporting mistrust - or from medical institutions not caring much about whether Black patients were being treated fairly.

Chapter Summary

In summary, a trend persists in which the healthcare needs and concerns of Black patients are routinely dismissed, downplayed, or leveraged against the patient as a product of their own wrongdoing. This chapter has established that once the hospital movement in the United States gained traction and designated more visible venues in which healthcare could take place, not only was it easier to document differential treatment by providers, but more striking evidence emerged of the extent to which American medical training and practice emphasized that Black patients are less deserving of access to high quality healthcare than their white counterparts. As a result, with the advent of institutionalized segregation, such ideologies were given free reign to dominate healthcare facilities, granting justification to the outright denial of care to Black patients in the eyes of white practitioners. These ugly consequences of southern antebellum medical ideologies seeped into subsequent classes of trainees, embodied in such examples as the Tuskegee Syphilis Study and Tressie Cottom's ignored attempts to save her fetus. But just as readily as Black patients' perceived unworthiness of medical treatment spread amongst medical circles, words of caution that white practitioners harbored ill intent have circulated in Black communities for several generations, parallelling one another. In the following chapter, the voices of present-day Black patients based in the South are given center stage in the conversation

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[122] Keith Wailoo, "The Feminine Mystique of Self-Examination," in *How Cancer Crossed the Color Line* (New York: Oxford University Press, 2011), 74.

surrounding how continued maltreatment by medical practitioners influences Black communities’ continued mistrust of medical care in the South, the birthplace of many of the aforementioned racist medical logics.

Chapter 3

Where Are We Now?

Chapter Outline

The Hippocratic oath, which guides western medical philosophy, holds that doctors must "First, do no harm."[123] Despite the common perception of this principle as central to medical practice, it is routinely broken when United States medical professionals weaponize antebellum medical ideologies against Black patients they see. Unethical clinical researchers' intentional targeting of Black communities for unsuspecting research participants, intentional neglect of Black patients' suffering, and segregated medical care throughout US history grossly violate this tenet of medical care. Unsurprisingly, such sweeping, unchecked injustices in the medical field have tarnished the reputation of medicine in the eyes of many African Americans, fostering a fear of healthcare professionals and hesitation to seek treatment. But history alone does not explain why medical mistrust persists; many of the racist teachings and norms within medical practice and training are still alive and well today. For example, contradictory to the vast body of journalists, healthcare workers, and common folks who directly attribute COVID-19 vaccine hesitancy in Black communities to the infamous Tuskegee Syphilis Study, many African Americans who are vaccine-hesitant have skepticisms based in the long history before, and the events since, that infamous US government-funded study.[124] In this chapter, interviews with African American adults based in the South will paint a picture of medicine as an entity with a duty to help, but a reality of causing much harm, with many examples of racist encounters with medical professionals occuring in the here and now. These interviews are supplemented with recent documentary and media accounts narrating southern African Americans' personal

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[123] "Greek Medicine – The Hippocratic Oath," National Library of Medicine, National Institutes of Health, last modified February 7, 2012, https://www.nlm.nih.gov/hmd/greek/greek_oath.html.

[124] Rogers, "Tuskegee."

experiences with medical professionals who crudely dismissed their symptoms, chastised them for not seeking earlier treatment (despite their every effort to do so), and interacted with them in ways riddled with racist undertones.

Interview Methodology

For the interviews detailed in this study, African American adults who were born and raised and/or currently work in the American South were recruited to answer three questions about their experiences with medical professionals:

1. What comes to mind when somebody mentions doctors, nurses, or other medical professionals?
2. Have you ever felt disrespected by a doctor or other medical professional? If yes, why do you think they were being disrespectful?
3. Have you ever been scared or afraid to visit a doctor? If yes, please describe in however much detail you are comfortable with.

A total of four interviews were conducted between January and February, 2022. Interviewees spanned in age from 23 to over 50 and are all currently based in the metro Atlanta area, with three interviewees indicating they were raised in the South as well. Two identified as male, and two identified as female, and though all identified as Black or African American, one additionally identified as the child of Igbo-speaking Nigerian immigrants. Of particular note, one of the interviewees is a current medical student. One potential weakness in the soundness of the oral histories collected here is that when interviewees described their negative interactions with medical professionals, they were not asked - nor did most of them indicate - the race of the practitioner who treated them negatively. This question was not asked due to caution surrounding “leading questions,” which may skew an interviewee’s answer especially if they believe the interviewer is hoping for a specific outcome.

Duty to Heal

All interviewees associated the terms “doctor,” “nurse,” or “medical professional” with health, healing, and helping. Originally, the hypothesis was that if medical mistrust was widespread in modern-day Black communities in the South, these terms would be associated with fear or an imbalance in power dynamics between them and the interviewee. However, the ready association of medical professional titles with the task of healing and providing healthcare draws upon an underlying truth to the medical field: those who practice medicine are *supposed* to heal and ensure the health of patients, with the understanding that this applies to patients of all races, genders, and other identities. One interviewee in this study - a current medical student - grew up in an immigrant Nigerian community in which many women were nurses, leading her to express familiarity and a sense of comfort with medical professionals as a whole. However, this participant later revealed multiple discomforting experiences with medical professionals as a patient, including being talked down to, as other interviewees have reported. This is an example of trust that was built but later frayed, but also an attestation that it *is* possible to build trust of medical professionals within southern Black communities once they operate as members of the community. All patients are entirely within their right to believe that medical professionals will treat them, regardless of their race. When that duty is failed, it is an injustice to patients and their families and communities who bear the losses.

Echoes of this rightful expectation can be found in the documentary “The Cost of Black Motherhood in Mississippi,” during which journalist Soledad O’Brien interviews Black people who have been pregnant, given birth, or lost a loved one in childbirth, in Mississippi. One of O’Brien’s interviewees was Rakiya Ward, a 24-year-old Black mother of two whose last pregnancy ended in miscarriage despite her raising the alarm aboutn her baby’s abnormally rapid heartbeat and cessation of movement. Ward told O'Brien, "I trusted y'all with me and my baby."[125] Due to this miscarriage, she felt anxious about her pregnancy at the time of filming, having hired a Black female doula to support her in the hopes that this baby would be delivered, healthy and safe. Ward's decision hearkens back to a practice during slavery in which Black women trained as midwives to support other enslaved Black individuals giving birth,[126] and echoes the decision of many Black patients to seek out Black physicians, often increasing their likelihood of seeking health screenings and services.[127] One may ask whether Ward truly did everything to prevent this miscarriage, especially in reference to the misconception that Black patients are too "lazy" to comply with medical regimens or treatment.[128] These assertions beg the question: whether or not she had been getting regular prenatal checkups, regardless of her weight or marital status, did she deserve to be ignored time and time again after she - in her own words - "cried out for help?" Moreover, despite what she told O'Brien, did she *trust* the healthcare system with her own health up until that point to regularly seek their advice? When these questions are considered, medical mistrust is understood as a complex phenomenon, leading to delays in seeking medical treatment even in situations where it is recommended – or considered "common sense" – including during pregnancy. Thus, it is crucial to refrain from blaming patients for not making use of healthcare services, and instead comprehend the responsibility of

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[125] "The Cost of Black Motherhood in Mississippi," in *Disrupt & Dismantle*, Season 1, Episode 6, directed by Soledad O'Brien, Black Entertainment Television, March 24, 2021, 0:4:43.

[126] Fett, "Spirit and Power," in *Working Cures*, 33-35 & 53-59.

[127] Alsan, Garrick, and Graziani, "Does Diversity Matter?", 4075 & 4107; Saha et al., "Patient-Physician Racial Concordance," 1002; Ryan Huerto, "Minority patients benefit from having minority doctors, but that's a hard match to make," *University of Michigan Health Lab*, March 31, 2020, https://labblog.uofmhealth.org/rounds/minority-patients-benefit-from-having-minority-doctors-but-thats-a-hard-match-to-make-0.

[128] Lisa A. Cooper et al., "The Associations of Clinicians' Implicit Attitudes About Race with Medical Visit Communication and Patient Ratings of Interpersonal Care," *American Journal of Public Health* 102, no. 5 (2012): 981, https://dx.doi.org/10.2105/ajph.2011.300558; Mark Peffley, Jon Hurwitz, and Paul M. Sniderman, "Racial Stereotypes and Whites' Political Views of Blacks in the Context of Welfare and Crime," *American Journal of Political Science* 41, no. 1 (1997): 30–60. https://doi.org/10.2307/2111708.

medical practitioners to uphold their promise of working for the betterment of health, no matter who the patient is.

One respondent associated the titles of medical professionals with a multitude of opinions. In addition to their elevated status and some of the great doctors this individual has been seen by, she also recalled some of the “crappy” doctors she has experienced, in addition to the arrogance by some medical professionals which led to the deaths of people she loved. Later, she shared a deeply personal loss she experienced due to medical negligence, which still weighs on her. A childhood role model in her community, who was a Black woman, presented to a doctor with pain while urinating. After her symptoms were dismissed, she landed in the emergency room some time later and was diagnosed with bladder cancer. By that time, it was too late; the cancer had metastasized, and within a matter of weeks she had passed away. Similarly, a colleague of this interviewee presented to her physician with head pain. He dismissed it as caused by “stress.” Not believing his word that something as simple as stress could explain such excruciating, consistent pain, she called her daughter and asked what to do. Her daughter’s reply was to go to the emergency room, the logic being that she could receive a “real” diagnosis there. The daughter’s advice may have saved her mother’s life; the emergency room found that she had a brain tumor.

These stories, said the interviewee, are part of her frustration with the misplaced anger of white Americans on African Americans for supposedly driving up the cost of healthcare by using the emergency room frequently. She stressed that the emergency room is where Black patients, having no luck getting a diagnosis from a general practitioner, can get a real diagnosis. As this interviewee said, and as statistics demonstrate, African Americans are more likely to go to the emergency room for medical care than white patients, even for non-urgent health concerns.[129] Though racial differences in insurance levels may partially explain this trend,[130] given this interviewee's story of her colleague going to the emergency room to receive a "real diagnosis" for what ended up being a brain tumor, one must wonder whether medical professionals' intentional avoidance of performing appropriate tests on Black patients is part of the equation. And, as in the case of this interviewee, stories of the audacity of some medical professionals to dismiss potentially life-threatening symptoms drastically diminishes anyone's ability to trust their health in trained practitioners' hands.

Respectability Politics & Perceived Worthiness of Receiving Care

When asked whether they had been disrespected by medical professionals, 3 of the 4 interviewees gave a firm "yes." One participant, a 37-year-old Black male working in Atlanta, reported having experiences in which doctors appeared to have a limited understanding of his cultural background and talked down to him as though he was unintelligent. He found this behavior particularly disconcerting because he holds a Ph.D. and is thus well-educated and highly capable of understanding information conveyed to him by medical professionals. Another interviewee, a Black female scholar over age 50, reported that while living in Columbia, Missouri, she asked her doctor if she could get a mammogram. Her doctor rebutted that she did not need one, as it was not medically required. After she cited a recent Congressional ruling enabling coverage of mammography, the white male physician retorted with "you must be one of those feminists." Both cases demonstrate the acceptability for practitioners to deny Black patients authority over and knowledge of their own bodies. The same denial of agency over

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[129] Layla Parast et al., "Racial/Ethnic Differences in Emergency Department Utilization and Experience," *Journal of General Internal Medicine* 37, no. 1 (2022): 52, https://dx.doi.org/10.1007/s11606-021-06738-0.
[130] Parast et. al., "Racial/Ethnic Differences," 54.

Black peoples' own bodies and health enabled J. Marion Sims to assert that his victims were experiencing pain without consulting their version of the story first. The fact that these attitudes from medical professionals are still tolerated more than a century after Dr. Sims's experiments points to medical training as a culprit in making trainees inherit a disdain for Black patients' familiarity with their own bodies. Speaking directly to this issue is a comment made by the latter interviewee, whose doctor brought a medical trainee with him during the appointment. The interviewee expressed feeling sorry for the trainee, as they would have learned in that moment that white medical practitioners' disregard for Black patients' decision-making when it comes to their own bodies is acceptable. This interaction illustrates the venue in which trainees are inundated with anti-Black bedside manners and conduct. There is no shortage of literature on pedagogy in medical schools that stresses that medical students - and by extension, physicians' assistant students, nursing students, and other trainees - learn much of their conduct towards patients from practitioners they observe in clinical settings.[131] Additionally, these studies state that if part of that learned conduct is discriminatory, then trainees internalize that attitude into their interactions with patients once they become independent, licensed practitioners .[132] In summary, the interviewee had plenty of reason to be concerned for what her doctor's trainee would take away from that appointment.

The question regarding whether interviewees have ever been scared or afraid of seeing a medical professional produced mixed responses. One respondent, a 37-year-old Black male, reported that during his teenage and young adult years, he worried that medical professionals

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[131] Karnieli-Miller et al., "Hidden Curriculum," 369-377.

[132] Karnieli-Miller et al., "Hidden Curriculum," 369-377; Megha Shankar et al., "Presence 5 for Racial Justice Workshop: Fostering Dialogue across Medical Education to Disrupt Anti-Black Racism in Clinical Encounters," *MedEd PORTAL* 18 (2022): 11227, https://dx.doi.org/doi:10.15766/mep_2374-8265.11227; David Acosta and Kupiri Ackerman-Barger, "Breaking the Silence: Time to Talk About Race and Racism," *Academic Medicine* 92, no. 3 (2017), doi: 10.1097/ACM.0000000000001416.

would act and relay information rudely towards him, and that getting an appropriate health assessment would prove difficult due to their attitudes. He did, notably, report that once he received his Ph.D., he felt an added sense of credibility as a patient, diminishing his fears that medical professionals would talk down to him or neglect his health. This is a small taste of the respectability politics Black patients have had to navigate in the U.S., echoed in the case of a patient treated by Dr. Esther Choo, in the summer of 2020. In a tweet that has received nearly 100k likes, Dr. Choo shared the story of a badly-injured Black man she attended to in the emergency room. When she spoke with the patient's family and asked if they had any questions, the doctor reported, "They told me that he worked for [a well known company]. And that he was a [respected professional] at that company. That he was on his way to work. That he is loved in the community. A good brother and son. That he was well dressed before the blood soaked his clothes."[133] As Dr. Choo's tweet thread continued, she was heartbroken at the necessity this family felt to justify their brother and child's worthiness of being treated, as if his condition alone were not enough. This family's awareness of the medical system's disregard for patients deemed unworthy of care, such as Black patients, led them to build this man's reputation in a positive light before addressing the "chief concerns" Dr. Choo describes - "when can [I] see him, when does he get out of surgery, do you know his meds and allergies, his mama gets to go in first"[134] - that should have been more on the forefront of their minds than the patient's worth in the eyes of the doctor. Though the 37-year-old interviewee did not report any experience as serious as Dr. Choo's example, a system in which credibility and worthiness have to be

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[133] Esther Choo, "They told me that he worked for [well known company] And that he was a [respected role] at that company That he was on his way to work That he is loved…" Twitter, August 7, 2020, https://twitter.com/choo_ek/status/1291811273181507584.

[134] Esther Choo, "Nothing in recent memory has broken my heart as much as gradually realizing that a family of a shattered man whose chief concerns should have been…" Twitter, August 7, 2020, https://twitter.com/choo_ek/status/1291812132640571392; Esther Choo, "...had to worry that the racism inherent in the system and in people everywhere meant they had to spend their few moments with me putting him in a favorable light…" Twitter, August 7, 2020, https://twitter.com/choo_ek/status/1291813223507742720.

established prior to receiving proper medical treatment is not one which adheres to the healing philosophy of medicine.

Mistrust of Medical Professionals

The interviews here revealed several examples of the continued toleration of medical professionals who get away with neglecting the health of Black patients. As a result of this pattern, regardless of whether it was pinpointed to a specific experience–or a combination of experiences and collective memory–there was apprehension among Black patients towards medical professionals as a whole. In some cases, this apprehension turned into suspicion and mistrust of medical professionals, leading these interviewees to come to doctors' appointments with a heightened sense of awareness (such as recognizing that they may need to correct or confront practitioners), greater caution (such as being more selective with which practitioners are allowed near them), and outright fear - from the fear of receiving bad news to the fear of being spoken to condescendingly, or worse.

Speaking most directly to issues surrounding medical mistrust, the same Black female scholar reported an encounter with a dentist as a child. For context, her dentist was a white male in a neighborhood that had undergone a demographic transition from majority-white to majority-Black. As he was cleaning her teeth, he grumbled about how "these people," referring to working-class African Americans, were "destroying" his neighborhood. Like Walt Kowalski in the movie *Gran Torino*, he perceived the introduction of communities of color into his neighborhood as an insult to his whiteness. Grumbling about this transition in the neighborhood's racial demographics while caring for a young child reinforces just how pervasive practitioners' biases are: if his attitude towards a child is waterlogged with hatred over her community - as this scholar said, "*my* people" - can he be trusted to give her the best care he can? Presumably not, as she reported avoiding dentists for an additional decade following this incident. Though this case is unique from others presented here in that the practitioner's biases are explicitly verbalized, the aftermath is the same. Recognizing the presence of that bias coming from somebody tasked with one's care, even in a single interaction, has the potential to inhibit one's faith in practitioners as a whole.

Interview Limitations

Finally, something that cannot be ignored in these interviews is the gender disparities in reported mistrust of, or disrespect from, medical professionals. The only participants who reported never being disrespected by a medical professional, or never attributed fears of medical professionals to past discrimination, were cisgender males. In addition to racial differences in medical mistrust, individuals who are not cisgender males tend to report more encounters with medical professionals who have displayed bias towards them, along with greater hesitancy in seeking medical care. When intersectionality – described by Kimberle Crenshaw as how race, gender, class, and other categories intersect to define an individual's experience in society[135] – is considered in the context of medical mistreatment and mistrust, one can see how experiences with medical professionals can be informed by multiple identities. Individuals who are female, gay, transgender, poor, disabled, overweight or obese, and other marginalized identities, have been found to report more negative interactions with practitioners in surveys that controlled for race. Moreover, in the South specifically, where investments into healthcare are among the lowest in the nation,[136] and the rights of queer and female individuals are consistently under

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[135] Kimberle Crenshaw, "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics," *University of Chicago Legal Forum* 1989, no.1 (1989), http://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8.

[136] O'Brien, "The Cost of Black Motherhood in Mississippi."

attack by lawmakers,[137] not to mention high poverty rates,[138] these intersections can be expected to greatly exacerbate medical mistrust and fears of seeking medical care. Though the interviews in this thesis did not ask about, nor control for, socioeconomic status, sexual orientation, disability, weight, or whether individuals were non-cisgender, future studies should explore how these categories intersect with Blackness to inform one's experiences with, and ability to trust their health in the hands of, medical professionals in the U.S. South. Still, the stories told by this thesis's interviewees reveal a pattern of Black people having negative experiences in navigating the US medical system, particularly in the South, a one-time Mecca of medical practitioners and health science knowledge-seekers in the antebellum era.

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[137] Priya Krishnakumar, "This record-breaking year for anti-transgender legislation would affect minors the most," *CNN*, April 15, 2021, https://www.cnn.com/2021/04/15/politics/anti-transgender-legislation-2021/Index.html; Elizabeth Nash, "State policy trends 2021: The Worst Year for abortion rights in almost half a century," *Guttmacher Institute*, January 12, 2022, https://www.guttmacher.org/article/2021/12/state-policy-trends-2021-worst-year-abortion-rights-almost-half-century.

[138] Emily A. Shrider et al., U.S. Census Bureau, Current Population Reports, P60-273, Income and Poverty in the United States: 2020, U.S. Government Publishing Office: Washington, DC, September 2021.

Conclusion

Where Do We Go From Here?

Thesis Overview

This thesis begins with the story of Annie Burton, a formerly enslaved woman whose distrust for castor oil prescribed by white physicians stemmed from the rumored fate of a lynching victim's body. Despite the folkloric elements of the story, the suspicions of Burton and other enslaved African Americans surrounding castor oil and white physicians more broadly [139] speaks volumes to a collective memory of the harm done by white practitioners to Black people and African American communities more broadly. These rumors are passed as "folklore," but the need for their existence and entrance into Black common knowledge tactfully informs African Americans that because white practitioners have the tendency to hurt them, they should not trust their care.

The cases addressed so far only scratch the surface of both medical abuses against African Americans and the collective memory of such abuses that lay at the root of Black patients' mistrust in medical practitioners in the American South. Though there is increasingly more scientific and sociological literature concerning BIPOC communities' mistrust of medical professionals, mistrust and the continuation of differential treatment are hidden in other findings. A 2018 study analyzing data in the New York Statewide Planning and Research Cooperative System database from 1999 to 2014 found that 42.6% of Black inpatient admissions for peripheral vascular disease had a limb amputated, compared to 28.6% of white inpatient admissions.[140] Considering that rigorous therapy was the alternative and amputation was

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[139] Stewart Culin, "Concerning Negro Sorcery in the United States," *The Journal of American Folklore* 3, no. 11 (1890): 285, https://dx.doi.org/10.2307/534066.

[140] Sahael M. Stapleton et al., "Variation in Amputation Risk for Black Patients: Uncovering Potential Sources of Bias and Opportunities for Intervention," *Journal of the American College of Surgeons* 226, no. 4 (2018): 641-49. https://dx.doi.org/10.1016/j.jamcollsurg.2017.12.038.

considered a last resort, these statistics beg the question of whether Black patients were truly offered the most extensive therapies before permanently limiting their mobility. In other words, do medical professionals caring for patients with vascular disease view Black patients as worthy of receiving high-quality treatment, or are they seen as just another patient to check off the list?

In this thesis, African American patients based in the U.S. South were interviewed regarding their experiences with healthcare professionals. The terms interviewees associated most frequently with medical professionals were along the lines of health, healing, and care. At the very least, these responses reflect what healthcare professionals' job is: to ensure *all* patients' health and, of utmost importance, do no harm. As previously mentioned, interviewees were not asked to identify the race of any medical professionals they have had negative–or positive–encounters with. However, it is worth pondering whether their responses would have differed if they had been asked the race of their physicians, especially considering the aforementioned statistics showing that Black patients generally have a preference for Black physicians,[141] along with the fact that Black patients who see Black physicians make greater use of healthcare services and screenings.[142]

21st Century Technology

Our current moment is one of struggle and triumph, setbacks and advances. Unique challenges are emerging and being met, particularly as we move into a more connected, aware, and digitized world. Just like many aspects of everyday life, racism in medical practices is moving into the digital sphere as well. A 2019 study published in *Science* reported racial bias in a commercial algorithm widely used by hospitals and insurance providers, created to "identify which patients will benefit from 'high-risk care management' programs, which provide

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[141] Huerto, "Minority patients."
[142] Alsan, Garrick, and Graziani, "Does Diversity Matter?", 4075 & 4107.

chronically ill people with access to specially trained nursing staff and allocate extra primary-care visits for closer monitoring,"[143] with the goal of reducing serious illness complications in those most at risk. This algorithm utilized patients' prior healthcare spending to determine their healthcare needs, such that those who had spent more on healthcare in the past were considered to be of lower risk. However, Black patients' more frequent emergency visits and greater likelihood of chronic illness compared to white patients means that even when Black and white patients had the same healthcare spending, Black patients' greater healthcare needs were not reflected in the algorithm. Possible causes of bias within this algorithm included Black patients' relatively lower income, combined with poorer patients' overall tendency to seek healthcare services less frequently than their wealthier, and in this case ostensibly white, counterparts. Researchers also pointed to Black patients' overall mistrust of medical practitioners as a contributor to their lower likelihood of seeking medical interventions, leading to greater incursions of medical costs when delays in seeking care give way for more precarious health situations to arise.[144] Identifying biases within algorithms undercuts the notion that digitizing healthcare-related information may erase human-created biases. This is not possible until those who designed these algorithms are fully aware of their real-world performance and the racism already entrenched into the field of healthcare, and the mistrust and other domino effects it has on diverse communities. After all, humans - each with their own biases - create algorithms and other AI technology.

On the other hand, technology may make practitioners' biases against Black patients more visible, providing a unique opportunity to address racism within healthcare more directly.

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[143] Starre Vartan, "Racial bias found in a major health care risk algorithm," *Scientific American*, October 24, 2019, https://www.scientificamerican.com/article/racial-bias-found-in-a-major-health-care-risk-algorithm/, para. 2.

[144] Vartan, "Racial bias."

A study published in January of 2022 by University of Chicago researchers produced a report of 40,113 electronic health records created between January 2019 and October 2020 which contained at least one negative descriptor of the patient. Black patients were 2.6 times more likely than their white counterparts to be described with negative terms such as "resistant,"[145] "noncompliant,"[146] and "aggressive."[147] Though the study was limited to health records available at a single undisclosed urban medical center, the digitization of patients' health records made this study, along with its relatively quick data collection, possible. Moreover, with greater social attention to microaggressions and manifestations of implicit racial bias in everyday life, due in part to the 2020 racial awakening and our aforementioned greater digital interconnectedness, stories of racism and mistrust in medicine are widely accessible to the general public. On platforms such as Twitter, users can easily share personal encounters with medical professionals steeped in racial bias,[148] practitioners can share the manifestations of mistrust and power imbalances they see in their day to day shifts,[149] and scholars can update users on new scientific literature taking aim at the deep-seated anti-Black practices and attitudes which still shape

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[145] Michael Sun et al., "Negative Patient Descriptors: Documenting Racial Bias in the Electronic Health Record," *Health Affairs* 41, no. 2 (2022): 208a, https://dx.doi.org/10.1377/hlthaff.2021.01423.

[146] Sun et al., "Negative Patient Descriptors," 206.

[147] Sun et al., "Negative Patient Descriptors," 208b.

[148] B. Brian. Foster, "They want to talk drugs. And for most of the ride, it feels like that is all that they do. We arrive to the Emergency Department of @uvahealthnews…" Twitter, February 4, 2022, https://twitter.com/BBrianFoster/status/1489706001586655242; B. Brian Foster, "Enter Nurse. It is mostly awkward small talk, which I'm struggling to keep up with, until it isn't. Nurse: 'So, what, were you at a party…and things got out of control?'..." Twitter, February 4, 2022, https://twitter.com/BBrianFoster/status/1489706002907815946; B. Brian Foster, "I can't talk without pausing frequently to breathe. Me: Breathe. 'I don't' – breathe – 'Know' – breathe – 'Bloating' – breathe – 'Tightness' – breathe – 'In my chest'..." Twitter, February 4, 2022, https://twitter.com/BBrianFoster/status/1489706008570179592; B. Brian Foster, "I talk about my symptoms until I'm done. NP: 'Okay, so what all drugs were you using?' What comes after astonishment? NP tells me these are standard questions…" Twitter, February 4, 2022, https://twitter.com/BBrianFoster/status/1489706012122787850; MimZWay, [Replying to @uche_blackstock and @bigforkgirl] "This happened to my friend Melanie. I've attached her Ted Talk. Because her husband was a young, black man…" Twitter, February 5, 2022, https://twitter.com/MimZWay/status/1489967905907384324?t=Xz-_SqB-PsenhIm88E6RA&s=03.

[149] Esther Choo, "They told me…"; Esther Choo, "Nothing in recent memory…"; Esther Choo, "...had to worry that the racism inherent in the system…"

American medicine.[150] Everyday people can engage with these tweets, hear stories, and learn about racial bias within medicine via an app already at millions of users' fingertips.

COVID-19 Pandemic

Maintaining the focus on the 21st century, various data concerning the COVID-19 pandemic in the United States has highlighted how both wrongdoing by medical practitioners and African American patients' mistrust in medicine are still alive and well. In February of 2022, a report from the Kaiser Family Foundation revealed that since April 2020, though COVID-19 cases in Black and white patients had an equal age-adjusted risk of contracting the virus, Black patients were 1.5 times more likely to be hospitalized and 70% more likely to die of the virus.[151] Though the pandemic and its fallout extend far beyond the South, it should be remembered that the legacies of mistrust and intentional medical mistreatment of Black patients is rooted in antebellum medical practice, literature, and attitudes of practitioners. As Dr. Fatima Cody-Stanford and Simar Singh Bajaj reported, mistrust and present-day biases within healthcare cannot be chalked up solely to well-known cases, such as J. Marion Sims' experiments, Henrietta Lacks' story, and the Tuskegee study.[152] Instead, though these highly-visible cases anchor a well-known reality about clinical abuse of Black people, collective trauma in Black communities related to white medical practitioners such as in Josephine Bacchus and Annie Burton's narratives, and the almost-unchecked proliferation of racist attitudes by practitioners such as Kira Johnson and Serena Williams's stories, make for a large percentage of Black patients hesitant to seek healthcare, in tandem with a large percentage of practitioners objectively unwilling to offer them the highest quality of care.

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[150] Melanie Funchess, "Implicit Bias -- how it effects us and how we push through," TED, October 16, 2014, YouTube video, https://www.youtube.com/watch?v=Fr8G7MtRNlk&t=1s&ab_channel=TEDxTalks; Louie & Wilkes, "Representations," 38-42.

[151] Artiga et al., "Health coverage."

[152] Bajaj & Stanford, "Beyond Tuskegee," 2.

Additionally, the hesitancy of African Americans to seek medical care for fear of being utilized as a vehicle by which white researchers can profit from deliberate infliction of pain upon them is seen when analyzing demographic disparities in already hotly-contested COVID-19 vaccination debates. In a 2021 public service announcement encouraging vaccine-hesitant African Americans to get the COVID-19 vaccine, descendants of Tuskegee Syphilis Study survivors gave facts and clarified misconceptions about that study while sending the message that vaccinations save lives.[153] When racial gaps in early vaccination rates were first reported, studies were quick to blame Tuskegee for low vaccination rates in Black communities.[154] However, there are major logical errors with this contention. First, contradictory to the idea that Tuskegee causes mistrust in COVID-19 vaccines, vaccines are administered for the purposes of healing and prevention of disease. Tuskegee, on the other hand, was infamous for *withholding* medicine from its subjects. Second, as this thesis establishes, medical mistrust comes more from a generations-old legacy of medical professionals intentionally harming or refusing to heal Black patients. Major, nationally-recognized cases such as Tuskegee do exacerbate mistrust, but the foundation had already been laid for African American communities to lack trust in medical professionals due to both personal experiences and generational trauma related to practitioners and clinical research.

It may be asked why the onus is on white medical practitioners to rid themselves of biases, and not on Black patients to build trust in medicine. In the United States, medicine was developed and advanced not *for* Black patients, but rather on their backs. As previously analyzed, some of the most widely-used, life-saving medical tools and procedures today were

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[153] Ad Council, “Tuskegee Legacy Stories | COVID-19 Vaccine Education Initiative,” June 30, 2021, YouTube Video, https://www.youtube.com/watch?v=B0Vb7O121_8&ab_channel=AdCouncil.

[154] Bajaj & Stanford, “Beyond Tuskegee,” 1; Kristen Rogers, “Tuskegee isn't the only reason why some black people are hesitant to get the coronavirus vaccine,” *CNN*, March 30, 2021, https://www.cnn.com/2021/03/30/health/tuskegee-syphilis-study-vaccine-distrust-reasons-wellness/index.html.

developed by minimally-regulated experimentation on often unwilling or strongly pressured Black subjects. When considered alongside the multilayered attacks on Black health, from the institutional level of segregation in hospitals to the individual level of refusal to provide necessary care - not to mention the permeation of these phenomena even today - it becomes clear that American medicine never deemed Black people worthy of care, health, and survival. Furthermore, insisting that Black patients do the work in bridging mistrust echoes a familiar trope that Black people are lazy and noncompliant,[155] insinuating that *they* must be the sole contributors to achieving equity.

Where Do We Go From Here?

Finally, the question of "where do we go from here?" is prompted. I asked this question to an emergency medicine physician who also serves as a professor and Vice-Chair of Faculty Equity, Engagement and Empowerment at a medical school in the South. She said that change starts in medical education.[156] As previously mentioned, Karnieli-Miller et al. emphasized the "hidden curriculum,"[157] during which medical trainees learn how to navigate interpersonal interactions in the clinical setting, as the prime time when trainees engrain racial biases into their practice. Just as students can learn to be racist during this training period, they can also learn to be anti-racist, as delineated in a February 2022 AAMC review of medical teachings such as Presence 5, a DEI-developed framework which emphasize listening to and connecting with patients to eliminate the role of racial bias in clinical encounters.[158] Worth mentioning is the lack of scholarship pertaining not to students who learn racist medical practices during their medical education and training, but students who *enter* their medical studies with pre-existing anti-Black

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[155] Cooper et al., "Associations of Clinicians' Implicit Attitudes," 981; Peffley, Hurwitz, Sniderman, "Racial Stereotypes," 30–60.

[156] Henry Mangalapalli, interview with Dr. Sheryl Heron, personal Interview, Atlanta, March 14, 2022.

[157] Karnieli-Miller et al., "Hidden Curriculum," 369.

[158] -Shankar et al., "Presence 5," 11227.

attitudes. A 2016 study, known for its finding that close to half of first- and second-year medical students believe Black patients feel less pain than white patients, also reported that 73% of the lay public believed at least one provided false belief about biological difference between Black and white bodies was true, compared with 50% of medical students and residents.[159] Since pre-medical and incoming medical students exist somewhat between the ranks of lay public and active medical students, it can be reasonably extrapolated that the percentage of this demographic who holds false beliefs about Black and white biological difference is somewhat between 50% and 73%, which is nonetheless concerningly high. Such findings suggest that people enter medical training with pre-existing biases against Black patients. The aforementioned anti-racist medical curriculum is aimed at preventing these biases from translating into medical practice, but the life-or-death nature of many clinical situations beckons more active interventions specifically for students whose racism may not have been learned in traning, but rather far earlier in their journey to their medical studies.

As for building trust of medicine within southern Black communities, and Black communities across America, the interviewee who considered medical professionals as members of her community while growing up demonstrates a truth worth emphasizing. When medical professionals and interventions are incorporated *into* Black communities, not targeted against them, a trusting relationship is constructed. As one such example, for Black men with hypertension, interventions recruiting barbers to relay health information to Black men–combined with a medication regimen–proved more effective in leading to improvements than strictly clinical interventions.[160] Barbershops are cornerstones of Black communities across

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[159] Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations," 4298.
[160] Ronald G. Victor et al., "A Cluster-Randomized Trial of Blood-Pressure Reduction in Black Barbershops," *The New England Journal of Medicine* 378, no. 14 (2018): 1291-301, https://dx.doi.org/10.1056/NEJMoa1717250.

America and have more recently been recruited by medical and public health professionals to pass along health and safety information in response to COVID-19.[161] Similarly, the Black church–another landmark in Black communities–was recruited by the National Institutes of Health to encourage elderly Atlanta-area Black individuals to get the influenza vaccine in the 2013-2014 flu season.[162] Though these are just a sampling of examples, these cases substantiate the idea that consulting Black communities about utilizing approaches and information messengers that work for them without the paternalistic imposition of the white-dominant medical field ensures that Black communities have a central role in their own care.

Medical exaggerations about Black patients' tolerance of excessive pain, so-called physiological anomalies, and stereotypes about lung capacity are the seeds planted in the early colonial period which would spawn justifications for slavery and cruel experimentation. American medical practitioners and investigators have long developed therapeutics and treatments by crudely testing their efficacy and safety on a population deemed disposable enough should anything go wrong: African Americans. White satisfaction was thus gleaned by producing Black pain in two ways: by producing treatments (often unavailable to Black communities) through methods involving putting Black subjects through pain and severe discomfort, and by wielding constant reminders that Blackness renders a person perpetually in a sacrificial position to whites. Because of how deeply rooted medical perversions of the Black body are in American slavery and labor regimes in the South, and how intertwined those institutions are with the construction of the modern U.S., the consequences of medical mistreatment of Black people in the South literally built our society. Racist colonial and

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[161] Tracie White, "Community bonds help barbers improve health for Black men," *Scope*, March 8, 2021, https://scopeblog.stanford.edu/2021/03/08/community-bonds-help-barbers-improve-health-for-black-men/.
[162] Sahithi Boggavarapu et al., "Factors Associated with Seasonal Influenza Immunization among Church-Going Older African Americans," *Vaccine* 32, no. 52 (2014): 7085-90, https://dx.doi.org/10.1016/j.vaccine.2014.10.068.

antebellum medical literature and myths have permeated into modern medical teachings and knowledge, creating yet more generations of medical professionals who practice with racial biases, even if doing so unknowingly. As a result, African Americans' mistrust in medicine has renewed itself in each generation that suffers the consequences of anti-Black antebellum medical logics' new leases on life.

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