

## **Healthcare Liberation for Fat, Black, Disabled Women: White Supremacy in the American Medical System**

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*Systemic racism, sexism, disability discrimination, and weight bias impact Black women's health. Living under structures of white supremacy is directly correlated with long-term health disparities. Layers of stress associated with living in an ableist and fatphobic society increase negative health outcomes. This article shows how the intersection of race, gender, disability, and body weight deserves further interdisciplinary scholarship. Parallel discourses have emerged over the last few decades and lay a foundation for understanding the stress and trauma impacting healthcare delivery for women with intersecting identities and vulnerabilities.*

The healthcare avoidance (and therefore the negative health outcomes) of fat, Black, and disabled women directly connect to white supremacy. While weight stigma, racism, ableism, and sexism have been researched, the medical community has ignored how these intersectional layers of oppression interact. Further research on how these interactions impact healthcare is crucial for improving standards of care. Black people and fat women, for instance, have high rates of healthcare avoidance and lack of trust in doctors, due in part to historical medical exploitation.

I argue that we need an intersectional understanding of various issues and identities to improve health care for Black women in the United States. First, I discuss the United States' history of medical experimentation and health exploitation of Black people. This includes recognition of how the U.S. disability rights movement was largely led by white men and upheld pillars of white supremacy, which ensured the continuation of unique health inequities facing Black Americans. Second, I explore recent research centering on Cheryl Woods-Giscombe's (2018) "Superwoman Schema" (SWS) to show how Black women's daily stress affects their health. I also examine a "Fat Feminist Disability Framework" and discuss the importance of adding lenses of weight stigma and disability to form a more complete picture of American health care. Third, I analyze health care avoidance and how the knowledge of this

phenomenon can lead to a reconceptualization of the American medical paradigm. Ultimately, this article shows the need to examine white supremacy in the U.S. medical system and how various forms of discrimination impact the health outcomes of fat, Black, disabled women.

### **Historical Context**

Harriet Washington's (2006) coining of the term "black iatrophobia" to describe the unique fear and avoidance of medical care by the Black community has been under-utilized despite its value to medical scholarship. When searching "iatrophobia" in WorldCat, EBSCO, and other scholarly databases, the limited results do not include any articles that focused on Black health care avoidance; the search term "black iatrophobia" netted zero results. Indeed, research using the keyword "iatrophobia" prior to the publication of Washington's (2006) book *Medical Apartheid* was nonexistent. For example, some scholars use the term to discuss "white coat syndrome" and fear of needles regardless of race (see Stenehjem & Os, 2004; Murata et al., 2006; Martin & McGrath, 2014). Recently, Mara Hollander and Michele Greene (2019) called for further scholarship related to this term and an investigation of how fear of doctors and the health care system is affected by various identities. Importantly, iatrophobia is not irrational (as the original definition states), but is usually the result of trauma and negative past experiences with the medical community. However, Hollander and Greene (2019) neglect to even mention "black iatrophobia" or Washington's (2006) argument that contemporary Black fear and avoidance of health care stems from historical medical abuse in the African American strata. Regardless of intent, the redefining of iatrophobia is one example of how white supremacy is perpetuated in contemporary medical science; Black women scholars such as Washington (2006) have constructed necessary knowledge, but white scholars and practitioners must use this knowledge to untangle white supremacy from medical institutions.

Popular understandings of how the health care industry has navigated race in the U.S. encourage black iatrophobia. The notorious Tuskegee Syphilis Study,<sup>1</sup> for instance, has been widely discussed in popular culture through movies such as *Miss Evers' Boys* and numerous podcasts (such as *American Scandal* and *You're Wrong About*). The topic of medical exploitation of Black Americans often centers on Tuskegee and plays an oversized role in the American public imagination. (Once word got out about this study, the U.S. government halted the research and attempted to repair the damage by

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<sup>1</sup> The U.S. Public Health Service (USPHS) Syphilis Study at Tuskegee was conducted between 1932 and 1972 to research untreated syphilis. Researchers did not collect informed consent from participants and they did not offer treatment, even after it was widely available (Centers for Disease Control and Prevention, n.d.).

paying monetary damages and eventually offering a formal presidential apology in 1997. For some white Americans, Tuskegee is a distant memory that has been settled (Washington, 2006). The study was a blatantly racist and a eugenic abuse of power, yet Washington (2006) asserts that Tuskegee is only one of a “pattern of experimental abuse.” Further, “many African Americans understand it as such, because a rich oral tradition has sustained remembrances of pain, abuse, and humiliation at the hands of physicians” (Washington, 2006, p. 179).

Washington’s (2006) *Medical Apartheid* can be seen as a catalog of this pattern over the past 400 years, and it details the ways white people have tortured the Black body. Stolen Africans quickly learned they no longer had any autonomy as they were chained, starved, thrown overboard, and sold to the highest bidder. They had no right to care for themselves, to protect and care for their children, to adequate food and shelter, and no right to be treated as humans because they were not seen as human. Sick and elderly enslaved people were given, rented, sold, and traded to doctors who would administer experimental treatments prior to dispensing then-tested treatments to white people (Washington, 2006). Ironically, during a time when scientific racism was in full swing and white researchers believed that Black people were naturally inferior, physicians insisted on using their bodies to learn about white anatomy. The knowledge and trauma of these truths have been passed down generations through oral histories and in the DNA of descendants. Meanwhile, the experimentation and exploitation did not stop. For example: Consider Operation Sunshine and other radiation experiments that exploited poor, Black Americans, research on Black prisoners, XY studies on young Black boys without their parents’ knowledge, the theft of Henrietta Lacks’ cells (which changed medical research forever), and the use of unconscious emergency room patients as experimental subjects without consent (see Washington, 2006). Government admission of racially based medical exploitation has been lackluster at best, occurring very rarely. Although these situations are much rarer in the United States than they used to be, Black people continue to be understandably wary of providers who may appear trustworthy at first glance (Washington, 2006). Almost two decades after the publishing of Washington’s (2006) *Medical Apartheid*, the U.S. government still has not confessed to various medical studies carried out with state funding.

It is frustrating that the social movement that could recognize and accommodate health concerns in relation to Blackness, the U.S. disability rights movement, has on the whole ignored issues of race. In response, I call for a critical reading of the disability rights movement in relation to the pillars of white supremacy. This is not to say that we need to disregard the good that has come from the Americans with Disabilities Act (ACT) and other related policies. Rather, I argue that we must recognize

that white supremacy was intentional in the building of the United States and has influenced all of our institutions – and it will take just as much, if not more, intentionality to dismantle them. This includes, most certainly, U.S. medical institutions. While parts of the disability rights crusade were fashioned after civil rights actions (such as sit-ins) and certain actions were supported by the Black Panther Party and disabled Black people, we must consider how supremacy and white feminism impacted U.S. society’s understanding of disability and the laws that were created as a result. Tema Okun (2021) offers guidance by outlining several characteristics of white supremacy and how it can be seen in our behaviors and social structures: Perfectionism (believing we need to be perfect and others have to meet those standards of perfections, combined with being overly critical and unable to listen to different perspectives), paternalism (power holders assuming they are qualified to make decisions for others), either/or (presenting binary options such as right/wrong or with us/against us), progress is bigger/more (measuring progress with wealth and power), urgency (a sense of emergency facilitates the abuse of power), and individualism characteristics (the assumption that people should be able to do everything for themselves without assistance or accommodations). Exploring the connections between the disability rights movement and white supremacy will help us understand how society ignores fat, Black, disabled women’s experiences.

### **Recent Research: Linking the Superwoman Schema to Healthcare Avoidance**

While the U.S. history of medical exploitation and the disability rights movement is important to this discussion, recent research contributions regarding Black women’s health outcomes help us connect the past to the present-day. Woods-Giscombe (2018) generated the “Superwoman Schema” (SWS) to understand how the daily stress of microaggressions and overt racism interacts with Black culture and creates health disparities such as cardiovascular disease, diabetes, and high blood pressure. In the American culture of racism, the expectations placed on Black women create a feedback loop in which the stress they embody increases the health conditions they experience, in turn causing more stress. The SWS describes a mental model of how Black women show up for everyone in their communities except themselves (Woods-Giscombe, 2018). The framework consists of five major features that describe Black women’s perceived obligations: “to present an image of strength, suppress emotions, resist dependence on others, succeed despite limited resources, and prioritize caregiving over self-care” (Woods-Giscombe, 2018, p. 338). Woods-Giscombe (2018) uses her schema at the University of North Carolina for her ongoing research on mindfulness meditation to educate Black women about self-care and to lower negative outcomes. Research into the connections between the SWS and emotional eating,

inactivity, sleep issues, mental health, and other concerns for Black women is ongoing and advances the understanding of cultural paradigms and their effects on health disparities.

However, all of this knowledge does nothing if the patient continues to avoid visiting the doctor; the perception that doctors and hospitals are places where Black women will encounter oppression due to weight status, race, ability level, and gender should be taken seriously. Therefore, it is necessary to devise strategies to encourage women to enter the doctor's office to begin with. Research reinforces the belief that American medical institutions need to educate providers in cultural competence so that delivery models become more productive. For instance, a study by Seanna Leath et al. (2021) made connections between adverse childhood events (ACES) and negative long-term health outcomes, the SWS, and psychological afflictions. The Centers for Disease Control (CDC) reported in 2021 that 16% of the general population reported a score of 4 or higher on the ACES screener – a measure of childhood abuse and household dysfunction that connects to leading causes of death in adults – while 34% of the sample of Black women in Leath et al.'s (2021) study had the same score. Leath et al. (2021) explain that SWS is a “double-edged sword” which acts as both “an asset and a vulnerability” in that it allows Black women to cope with chronic stress but also serves to mask long-term depression and anxiety because of the internal and outsider perception of Black women being strong (p. 318). The masking of mental health struggles, along with lack of help from outside their immediate community, can make it difficult for Black women to medically address their emotional well-being. Lack of treatment for the chronic stress that Black American women experience creates further stress and long-term health issues (Leath et al., 2021). These findings emphasize the importance of bringing a balanced and nuanced approach to studying health care in the United States that considers the whole person – including their traumas and lived experiences.

Though there have been advances in studying Black women's health, research is still prone to weight stigma and posits fatness as problematic. Concepts of the ideal female body began with European colonizers projecting expectations of thinness onto African women, such as in the case of Saartjie Baartman<sup>2</sup>. Research connects the SWS and Black women's perceptions of barriers to weight management, for instance (Harris et al., 2022). These barriers are divided into categories of biological (genetics, lack of energy, medical conditions), psychological (lack of self-discipline, lack of motivation, self-conscious), and sociological (lack of access to a gym, financial issues, cultural food beliefs) reasoning

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<sup>2</sup> Human trafficked to Europe by a British doctor, Baartman was paraded around “freak shows” in London and Paris, with crowds invited to look at her large buttocks. Her case is seen by many as the epitome of colonial exploitation and the racist commodification of Black people (Parkinson, 2016).

for not being able to maintain a BMI of 25 or less. Charlie L. Harris et al. (2022) use weight management as an example of the self-care that is sometimes de-prioritized by Black women who feel pressure to exhibit strength and self-sacrifice for their families and communities. While this study does offer a lot of salient data, it is also an example of the overwhelming bias against larger bodies and the assumption that “obesity” is unhealthy. Rather than seeing weight as either a symptom of preexisting issues or an example of human variation, healthcare providers tend to see fatness as not only the cause of disease and illness, but as a disease unto itself. Harris et al. (2022) assume that women’s perceptions of “barriers to weight management” are factual rather than the result of internalized fatphobia. Fat women are used to having their pain and health concerns brushed aside with comments about how losing weight would alleviate these issues. What is the point of going to the doctor when an individual knows the provider is not going to take their needs seriously? If a health care visit means being humiliated and increased anxiety, it sometimes makes more sense to just stay home.

Research on binge eating and other eating disorders illustrate a need for cross-cultural understanding. Rachel W. Goode et al. (2020) did a systematic review of the literature related to binge eating among Black women. The authors state that Black women have similar or higher rates of binge eating than white women and that this behavior coincides with obesity at an even higher rate. Their research points out limitations in current eating disorders research, including how assessment tools may not be adequate in measuring eating disorder behaviors in Black women. For example, Goode et al. (2020) contend that cultural expectations surrounding the use of food for emotional support and eating larger portions of food may be related to lessened feelings of shame. (Research into Black women’s experiences with eating issues is lacking, but what research we do have suggests that there is less of a link between food and shame in the Black community. It’s not that Black women do not experience shame at all, but that there is less body shame or shame around using food for comfort than with white women.) However, feelings of shame are a criteria in diagnosing binge eating disorder, so this cultural difference appears to affect diagnostic results. There is also more acceptance of larger body sizes within the U.S. Black community, which could also relate to the lower likelihood of feeling shame. Results of another, broader study of eating disorders show that overall, white women and women of color with eating disorders exhibit similar levels of symptomatology, but when there were differences, it was women of color reporting more severe symptoms (Monterubio et al. 2020). Grace E. Monterubio et al. (2020) argue that more research is need on how eating disorders present in women of color and white women so that culturally competent treatment can be offered.

The medical community also disregards the importance of cultural foodways to whole body wellness. Within the Black American community especially, stereotypes about specific foods and appropriate food quantities can be harmful. Many of these ideas can be traced back to a colonial mentality that views difference as inferior. It is essential that medical schools are proactive about weeding out white supremacist concepts that lead to racial inequity in health services. Recent research highlights not only the need for further eating disorder research centered on Black, Indigenous, People of Color (BIPOC) women, but specifically on the need to interrogate measures and to examine cultural differences in beliefs around food and eating. Amy H. Egbert et al. (2022) point out that eating disorder researchers have discussed the need to study ethnic and racial differences for three decades and that there is an understanding that disordered eating is not just a white woman problem. Neha J. Goel et al. (2022) state that racial and ethnic minorities have already been shown to be underrepresented in the discipline, and an entire paradigm shift is needed despite some efforts to increase representation.

Recent scholarship provides us with the knowledge to bridge knowledge gaps, including understanding how Black women internalize obligations centered on surviving in white-dominated society and how they can be negatively impacted by stereotypes. The SWS shows that when Black people project an image of strength, it reifies the notion of the strong Black woman who needs no help. Black disabled women need to be able to externalize their valid feelings of anger and suffering, but doing so would put them at further risk of experiencing microaggressions and direct racism. Therefore, the feedback loop prompts Black women to stifle their emotions, leading to continued mental and physical illness.

## **Conclusions**

Examining the oppression of marginalized groups has become a viable and necessary academic endeavor, as indicated by the growth of fields such as women's studies, fat studies, disability studies, and Black studies. Academia has finally begun to look at disability history and how adding the lens of disability advances our understanding of race and gender (Baynton, 2001). Similarly, fat studies has attempted to humanize large bodied people, extracting the pathology that has been projected onto fatness. While these fields have contributed necessary knowledge, we have yet to fully integrate these findings into a productive plan to offer culturally competent and trauma-informed health care to fat, disabled, Black women. In fact, the white medical complex has largely ignored the related scholarship that Black women have worked hard to produce, such as Washington's (2006) concept of "black iatrophobia".

We need to investigate the ways that habits of white supremacy have burrowed into the American health care system. The disability rights movement and our cultural expectations about food and eating are two specific areas that require further study. The ways that Black Americans experience and react to being disabled are different from the experience of disabled white Americans, yet that difference is disregarded, and assumptions are made when accommodations are discussed and planned. Dieticians, nutritionists, and other providers also make harmful assumptions about fat, Black, disabled women's dietary habits. These assumptions are based on unconscious bias, and unpacking these ideas needs to be prioritized among medical students. Changing the way that we think about topics related to race and health will go a long way to improving health care delivery for fat, Black, disabled women.

More inclusive medical research requires more diversity in researchers, as well as in research respondents. Goode et al. (2020) argue that there have been systemic issues with recruiting, engaging, and retaining Black participants in binge eating studies. Goel et al. (2022) call for accountability in recruiting and retaining scientists in the eating disorder field that belong to marginalized groups, as well as in representation of minorities in research studies. Racial and ethnic minorities are underrepresented in the discipline despite limited efforts to increase representation, and a serious shift is needed. Recommendations for facilitating this shift include providing and maintaining "safe, inclusive, and supportive spaces" to preserve long-term careers for marginalized identities in eating disorder research, creating approaches to specifically recruit researchers from diverse racial and ethnic groups, and committing to the collection of comprehensive demographic information from interviewees and respondents (Goel et al., 2022).

The work of Moya Bailey and Izetta Mobley (2019) offer further guidance on how to interrogate the disability rights movement and root out white supremacy in the U.S. medical field. They describe their "Black feminist disability framework" as a structure which "centers race, gender, and disability, challenging these generally siloed theories to work together to better understand the realities for those multiply marginalized within society" (p. 19). Bailey and Mobley (2019) write that the historical and continued physical and mental violence experienced by Black people in the United States are traumatizing, and, furthermore, that trauma is disabling. They look at ways disability studies can incorporate the Black experience and how African American studies can include disability history to provide a more complete understanding of how these realms intersect. Bailey and Mobley (2019) raise valuable questions about white masculinity in the formation of the American understanding of disability, as well. The disability rights movement was spearheaded by white disabled men such as Justin Dart Jr.,

Ed Roberts, and Fred Fay – men who had no lived experience of how Black people in general, and Black women specifically, have experienced disability.

In his essay “Many Thousands Gone,” James Baldwin (1998) puts himself in the place of white Americans when he writes: “Our dehumanization of the Negro then is indivisible from our dehumanization of ourselves: the loss of our own identity is the price we pay for our annulment of his” (p. 20). The simultaneous medicalization and dehumanization of fat, disabled, Black women matters not only because they have value as human beings, but also because all health is bound up with Black women’s health.<sup>3</sup> The weight stigma that I experience as a fat white woman is bound up with the weight stigma that Black women experience. The sexism that I experience is bound up with the sexism that they experience. The ableism that I experience is bound up with the ableism that they experience. My liberation from these things is bound up with the liberation of Black women. We must work together to untangle white supremacy from U.S. medical institutions for all Americans to experience liberation.

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<sup>3</sup> These thoughts are inspired by the quote often attributed to Lilla Watson: “If you have come here to help me you are wasting your time, but if you have come because your liberation is bound up with mine, then let us work together.” Although she said this in a 1985 speech at the United Nations, Watson was uncomfortable with sole attribution as it came about collectively with an Aboriginal activist group (Sovereign Union, n.d.).

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