Reconstructing Equity: A deep dive into the factors that influence African American women's decision to pursue breast reconstruction

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Gabrielle Melton

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

Advisor

Caitlin D. Wylie, Department of Engineering and Society

Introduction

According to the reputable World Cancer Database, breast cancer remains the number one cancer affecting women globally at 12.5% ("Worldwide Cancer Data..., n.d.), and 45% of these women receive mastectomies, a procedure aimed to remove the tumor by removing the entire breast (More U.S. Women..., n.d.). Breast reconstruction surgery, aimed at restoring the breast using tissue from other parts of the body, is promoted on multiple cancer websites as a way to replace the lost breast. However, numerous authoritative studies conducted by prestigious institutions such as Dartmouth and University of Pennsylvania Medicine discovered that African American women are up to 55% less likely to receive breast reconstruction than Caucasian women (Minorities..., n.d.; Onega et al., 2014, 1). This disparity underscores a critical healthcare equity issue, indicating potential challenges for African American women in accessing breast reconstruction or opting against it despite the benefits highlighted on cancer websites. Diving into this research can help understand the sociotechnical problem surrounding the psychosocial factors that influence African American women's decision to pursue breast reconstruction surgery.

Extensive research has been conducted to analyze the individual factors that influence African American women to pursue breast reconstruction surgery. However, no literature has compared these factors to see how much one factor could stand above the others or how the combination of multiple factors could contribute to this racial disparity in the medical industry. I aim to use document analysis and STS theories, such as Critical Race Theory and Actor-Network Theory, to study these multifaceted variables. Critical Race Theory is a foundational academic framework that "examines the idea of race being a social construct, and that racism is not merely the product of individual bias or prejudice, but also something embedded in legal systems and

policies" (Sawchuk, 2021). One critical source I analyze is "Race After Technology" by Ruha Benjamin, which explores how technology and algorithms can reinforce racial biases (Benjamin, 2019). Actor-network theory can provide invaluable insight into how social media and technology influence body image and decision-making processes (Latour's Actor Network Theory, 2024). Additionally, Actor-Network Theory offers a lens to delve into the interconnected socioeconomic actors shaping the decisions of African American women (Latour's Actor Network Theory, 2024). From the analysis of body image, medical mistrust, and socioeconomic actors, I evaluate these influences and bring awareness to these healthcare disparities in breast cancer treatment.

Body Image

Contemporary societal norms' influence on body image is extreme and prevalent. Standards of women's bodies are shared and popularized, especially amongst younger generations, defining societal expectations of what a woman should look like. These beauty standards often vary based on social media influence, race, and culture. The theoretical framework Actor-Network Theory allows for a deeper analysis of this complex web of human and non-human actors. The actor-network theory aims to see sociological and technological factors as having an equal influence on a system (Latour's Actor Network Theory, 2024). It will be used to explore the interactions between social media, cultural norms, and African American women breast cancer survivors as they all intertwine to shape body image perceptions that influence these women's decisions about pursuing breast reconstruction.

The first actor to play a significant role in this network is social media, as it can sway African American women toward specific body images or their perceptions of their bodies. Algorithms that make up social media can be considered non-human actors as they are

manipulated and tweaked based on their creator and the users of that particular social media. These actors both perpetuate and popularize certain body types based on beauty standards created by changing generational perceptions and contribute to the pressure women feel about their appearance. These actors are also shown to affect women post-mastectomy, as many educational breast cancer information sites suggest that self-confidence and discomfort with body image can be improved with breast reconstruction. Given that body image is a popular subtopic addressed by cancer websites like the non-profit Susan G. Komen, which is supported by breast cancer survivors, one might assume that body image is of great concern to these women. (Body Image, n.d., Breast Reconstruction..., n.d.). Body image is also a considerable concern post-breast reconstruction surgery as well, as these websites also address that in post-procedure, "it will take time to adjust to the different way a reconstructed breast looks, feels and moves" and most address that the scars will heal and fade over time (Body Image, n.d., 62).

Furthermore, in addition to the already difficult mental journey that women face with breast cancer, 22.2% of women post-mastectomy experience depression and emotional changes, mourning the loss of their breast (Padmalatha et al., 2021, p. 526). Breast reconstruction is often presented to these vulnerable women as a way to feel more comfortable with their appearance, as the rate of depression following the procedure decreased to 15.7% (Padmalatha et al., 2021, p. 526). Rose, a participant in a study done by cancer and health disparity specialists focused on breast reconstruction decisions amongst African American women, described that "...it [reconstruction] gave me that feeling of still being a female...that was part of being female, having breasts" (Connors et al., 2021, p. 358).

The second non-human actor to have a significant influence is cultural norms that travel from generation to generation based on history, beliefs, traditions, race, and ethnicity. When

surveyed about preferential body types, African American women leaned more towards "a curvy/thick/toned body type," as that was the standard that was held growing up, along with it being popularized in contemporary culture (McComb & Mills, 2022, p. 167). This preference amongst African American women goes against the slender physiques that dominated Caucasian societal norms in media, and many African American women consider thinner physiques less desirable (McComb & Mills, 2022). This could be sustained by the representation of African American women having fuller curves in art, music, and media. Historical representations of African American women have also influenced present African American women as they have permeated through the years and slowly become the standard they grew up with.

The book "The African American Female Body: A Photographic History" by Deborah Willis and Carla Williams breaks this idea down further by going through cultural factors contributing to the stereotypes about African American women's bodies. The esteemed scholars behind the book conducted a historical visual analysis examining how African American women were portrayed in ways that emphasized curves and fullness, which were weaponized as they were labeled "exotic" and hypersexualized (Willis & Williams, 2002). The book also discusses how the colonialist gaze singled out the natural curves and body types of African American women, using these distinct features like curves or fullness to objectify and promote the thin Eurocentric beauty standard, ultimately exploiting them (Willis & Williams, 2002). This gap between Eurocentric and African American beauty standards throughout history has emphasized curvy body types, which can be seen in a quote from a participant in the peer-reviewed Awad et al. study: "I kind of thought that what it meant to be a black female was to be curvy" or another participant who said "...when Black people are growing up in most Black communities it is really pushed to be thicker" (Awad et al., 2015, p. 548). The deeply entrenched stereotypes and body

standards that have persisted throughout history in African American culture could exert a significant influence on the decision to pursue breast reconstruction surgery as a means to uphold and conform to the idealized curvy body image.

However, there are limitations to this, as another actor that should be considered is each African American woman experiencing life post-mastectomy, as they all have individual perspectives on post-operation options. Although body image has proven to be a reason to pursue breast reconstruction, it should be recognized that body image has also proven to be a reason against breast reconstruction. These fluctuating popular body standards have also birthed a body positivity movement, where African American women of different communities feel it is essential to recognize that every body type is beautiful (Griffin et al., 2022, p. 2). The rise in popularity of this movement in social media has inspired many to go against the harmful idealistic standards and accept that being an African American woman is more than your physical appearance. In the same study exploring breast reconstruction decisions, Nina, who did not undergo reconstruction, stated, "So much of womanhood, femininity is tied into our breasts, and it does not even matter... I do not mind the stares" (Connors et al., 2021, p. 359).

These statistics and analyses of actors in this network show that body image has a significant impact on the decision to pursue breast reconstruction. Paired with the evidence of a decrease in depression following breast reconstruction, one might assume that African American women would be more inclined to pursue breast reconstruction. However, the study conducted by the University of Pennsylvania Medicine that showed African American women are 24% less likely to pursue breast reconstruction as opposed to Caucasian women contradicts this statement (Minorities..., n.d.). Considering the disparity highlighted by this study, it becomes evident that despite the expectations drawn from the impact of body image on these decisions, other factors

such as medical mistrust, lack of representation in media, and socioeconomic disparities may also play significant roles in this challenging decision.

Medical Mistrust and Lack of Information

A long history of medical mistrust embedded in the healthcare industry has instilled fear in African American women when dealing with medical procedures. Although there have been several advancements in healthcare to solve this issue, ethical violations such as the use of Henrietta Lacks' cells without her consent for scientific breakthroughs (such as the polio vaccine and cancer treatments) have had tremendous impacts on the African American community as they have highlighted racism in medicine (Khan, 2011). Trust is an essential component of a healthy patient-physician relationship. Yet, these barriers make African American women uncomfortable and force them to rely on African American support groups or self-research to get the knowledge they desire. A quote from a participant in the Connors et al. study confirms this, saying, "Community was an important focus as women reported feeling excluded as African-Americans by the larger medical community. This exclusion by the medical community also underscored the need for self-advocacy in decision-making" (Connors et al., 2021, p. 361). Furthermore, the decision to undergo breast reconstruction following mastectomy is profoundly influenced by the level of information and awareness available. African American women have often decided not to pursue breast reconstruction, as physicians have not given sufficient knowledge to inform their patients.

As a way to fix this issue, New York mandated a public health law (NY PBH Law 2803-o), which required physician-patient communication about breast reconstruction options for women undergoing mastectomy. By requiring communication between physicians and their patients, the law aimed to relieve patients' ambivalence and give them the information to make

informed decisions about procedure options. A comprehensive study was done to assess whether this legislation would reduce racial disparities in post-mastectomy breast reconstruction rates (Mahmoudi et al., 2017). The data concluded that the law did not reduce disparities between Caucasians and African Americans but did reduce disparities between other women of color. The absence of positive progress, even with passed legislation, could be explained by ingrained medical mistrust persisting and instilling hesitation amongst African American women.

Furthermore, the lack of inclusion is perpetuated now in contemporary social issues due to the introduction of social media. African American women with breast cancer look towards the internet as a valuable resource to help them find more information about medical procedures such as breast reconstruction. However, many studies show that African American women are not represented in media posts related to breast reconstruction, which could potentially shed light on the decreased percentage of African American women pursuing this procedure (Hassan et al., 2021). From platforms such as Instagram, Facebook, and Twitter, a study done by plastic surgeons found that 6.7% of posts included patients of color, despite African American women being 13% of breast reconstruction patients (Hassan et al., 2021, p. 1215). African American women could have decided that, along with a combination of racist medical history and physician-patient mistrust, this underrepresentation could deter them from pursuing breast reconstruction, patient-physician distrust, and communication barriers may prevent African American women from feeling comfortable pursuing this complicated procedure.

These combined challenges can be further examined by employing Critical Race Theory to offer a new perspective on how systemic issues in the medical industry have been socially constructed to limit opportunities for African American women (Bridges et al., 2017). The long

history of taking advantage of African American men and women has set a precedent that has lasted and continues to affect today's contemporary social issues in healthcare. The mistreatment and exploitation of African Americans have embedded bias in physicians from studies conducted that only included a Caucasian population and, from this, a consistent feedback loop of underrepresentation. Due to this lack of representation and evidence of exploitation, African American women harbor a pervasive sense of distrust toward physicians (Shavers-Hornaday et al., 1997). This barrier created feelings of exclusion by the medical community that African American women have shared. It showed the structural racism over time that contributes to this distrust (Connors et al., 2021). It is also eye-opening that Critical Race Theory's relevance persists as the legislation that has been passed to address these racial disparities has not made a difference in treatment. Although it should be recognized that the Critical Race Theory can underestimate the complexity of enacting institutional change, the alarming proof of New York's public health law highlights the limitations of passing policy to fix these deep-rooted issues of racism.

Ruha Benjamin's book "Race After Technology" also provides an exciting perspective of Critical Race Theory in the context of social media's contribution to the underrepresentation of African American women. As Benjamin explores how technology perpetuates racial inequalities, she introduces an idea of "discriminatory design," where she explains that racism and bias are "magnified and buried under layers of digital denial" (Benjamin, 2019, Introduction). Social media apps such as Twitter contain algorithms that direct content to users that comply with what are considered the dominant social groups, perpetuating bias in relevant content. Benjamin perfectly details this issue by saying, "Even with the plethora of visibly diverse imagery...bias enters through the backdoor of design optimization in which the humans who create the

algorithms are hidden from view" (Benjamin, 2019, Introduction). Social media creators do not always consider cultural sensitivity related to healthcare content or are influenced by advertisers of reconstruction services or information that is not inclusive. This results in the marginalization of social groups such as African American women, promoting misrepresentation or underrepresentation, which then prevents these women from receiving crucial and accurate information. The social media platforms actively contribute to African American women's struggle to find proper information about breast reconstruction procedures, as these algorithms continue to place barriers that act as a biased maze for these women to navigate. Acknowledging these biases embedded in these algorithms can foster a change that eliminates marginalization and allows African American women to access resources about procedure information.

Mistrust in a patient-physician relationship and lack of information have been proven as factors that can deter African American women from pursuing breast reconstruction surgery. However, it is essential to acknowledge that these individual decisions are personalized through varying opinions and preferences paired with intense feelings following breast cancer treatment and mastectomy. A range of factors beyond race alone may also influence African American women's decisions to pursue breast reconstruction.

Socioeconomic Factors and Insurance Coverage

The confluence of insurance coverage and the network of socioeconomic actors that define status have also proven to play a pivotal role in whether African American women pursue breast reconstruction (Latour's Actor Network Theory, 2024). Private insurance plans typically have financial resources that increase access to healthcare benefits, such as lower out-of-pocket costs, a broader range of physicians, and more coverage options (The Difference..., n.d.). Public government-funded healthcare, such as Medicare or Medicaid, focuses on serving health

coverage to older adults and low-income individuals and families and typically has more restrictions on coverage in comparison to private insurance plans (The Difference..., n.d.). Depending on restrictions such as limited provider networks or reimbursement rates, it is more challenging to get surgeries such as breast reconstruction covered. As these types of insurance typically vary from state to state, an insightful study reviewing state-level data and plastic surgeon availability was able to conclude that Caucasian women with private insurance experienced the highest rate of immediate breast reconstruction. In contrast, African American women with public insurance saw the lowest rate (Yang et al., 2013). The findings of this study show the magnitude of this issue, given that, according to the U.S. Census Bureau, public insurance programs cover more African Americans compared to Caucasian individuals (Bureau, n.d.). This highlights the disparities in healthcare as there is a disproportionate impact of insurance coverage based on socioeconomic standing for African American individuals.

Looking further into this issue, an essential article evaluated data from numerous studies based on geographic location, comorbidity rates, insurance plans, and referral rates (Butler et al., 2021). These findings revealed that African American women faced obstacles due to all of these factors, presenting challenges that hindered breast reconstruction. To support this study, data from the Health Resources and Services Administration shows that African Americans are more likely to reside in areas with limited access to healthcare providers (Data Explorer, n.d.). Most of the literature covering racial disparities surrounding the type of insurance coverage or socioeconomic standing suggests that legislation should be put in place to intervene and solve these multifaceted issues (Butler et al., 2021; Yang et al., 2013). However, legislation has been passed to target these issues, yet progress has yet to be made. The Women's Health and Cancer Rights Act was a legislative attempt to solve this issue and mandate coverage for breast

reconstruction; however, African American women still face challenges in getting insurance coverage (Butler et al., 2021). One must question why, despite the implementation of legislation aimed at addressing these disparities, African American women continue to face challenges in accessing adequate insurance plans for breast reconstruction.

It is also important to acknowledge the possible overrepresentation of the African American community on Medicaid due to income inequality. Medicaid programs have implemented medically needy programs and spend downs as mechanisms for patients with substantial health needs to access healthcare services. These programs allow individuals whose income exceeds the regular Medicaid limits to qualify by "spending down" their income on medical expenses, making them eligible for Medicaid coverage (Medicaid..., n.d.). Despite these efforts, disparities in access to healthcare persist. The Affordable Care Act's Medicaid expansion on African Americans' access to healthcare was called into question, specifically, the rejection of Medicaid expansion in certain states, leading to fewer benefits to African Americans due to their overrepresentation in the states that rejected the expansion (Snowden & Graaf, 2019). An article by health policy experts Snowden and Graaf looks into this issue, focusing on how restrictions in Medicaid policies are shaped by racial bias and stereotypes about African Americans. These racial biases play into the idea of a population that is "undeserving" of healthcare, which hinders the improvement of healthcare access for African Americans (Snowden & Graaf, 2019). This creates a coverage gap, as coverage rates amongst African Americans remain lower than White Americans, further perpetuating disparities in the healthcare industry.

Furthermore, only low-income and elderly individuals qualify for public insurance; therefore, socioeconomic standing has a significant effect on breast reconstruction rates (Medicaid..., n.d.). Socioeconomic actors such as income, employment status, geographic

location, legal, health, or family status, and age form a network that influences societal opportunities, especially the type of insurance a person qualifies for (Becker & Newsom, 2003). Critical Race Theory can also be used to examine intersectionality and how these actors shape the decision to pursue breast reconstruction. African American women face multiple forms of discrimination and marginalization based on socioeconomic actors, which creates barriers to accessing certain healthcare services. The existence of systemic barriers toward African Americans has contributed to disparities that limit economic opportunities that may make it difficult for them to afford health insurance premiums or make them ineligible for coverage through employment (Racial and Ethnic..., n.d.). To address these disparities, exploring this network and, identifying social determinants of health, such as systemic barriers and economic status, and implementing policies that promote health equity will ensure equal access to healthcare services for African American women. Furthermore, improving the availability of healthcare providers within public insurance networks can help patients have easier access to specialized treatments such as breast reconstruction.

Conclusion

As breast cancer and mastectomy rates remain persistent, breast reconstruction will continue to be considered by each woman affected by it. The statistical findings from Dartmouth and the University of Pennsylvania prove that it is imperative to look into why these disparities are occurring and how significant of an impact they have (Butler et al., 2021; Onega et al., 2014). Through analysis of psychosocial factors using both Critical Race Theory and Actor-Network Theory, it can be concluded that body image, medical mistrust, and disparities in insurance coverage based on socioeconomic actors have a massive impact on African American women's decision to pursue breast reconstruction. However, the factor that has the most influence is the lack of information and inclusion of African American women. Whether it is in the media regarding information about breast reconstruction, clinical studies testing African American women to get unbiased data, or closing the insurance gap by expanding Medicaid to all states, this lack of inclusion has a detrimental effect on African American women. It has woven its way into each factor that plays a role in the systemic racism in historical policy and in contemporary societal norms that all impact African American women's decision to pursue breast reconstruction.

Although there are limitations to this study, such as geographical generalization or the complex individual nature of experiences that could affect the statistics, the consensus remains consistent. This inequity reflects the broader issues in healthcare that African American women face in getting access to specialized procedures such as breast reconstruction. Moving forward, more research needs to be prioritized to bring forth answers to reforming healthcare policies to ensure equitable access to breast reconstruction for African American women. Additionally, further investigation can be conducted on how social media can be used to promote the inclusion of African American women in medical studies and to enhance their access to comprehensive information. The implications of this analysis can extend to physicians, politicians, and the general public, bringing awareness to these racial disparities stemming from systemic inaction and societal norms, potentially leading to improved access to breast reconstruction, equity, and enhanced psychosocial well-being.

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