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Share My World: Illuminating The Experience of Black Uterine Fibroids Patients and the Need
for Implicit Bias Awareness and Cultural Competence in Their Reproductive Care

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Abstract

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By
Kierra B. Grayson

Background/Intro: Black women are disproportionately burdened by uterine fibroids. The benign tumors impact their lives physically, mentally, emotionally, and financially.

Project Goal: This special study project aimed to identify opportunities to address implicit bias as a barrier to care for Black uterine fibroid patients and improve patient outcomes impacted by the implicit bias.

Methods: An extensive literature review was conducted on four databases. Thirty relevant sources were identified. Outreach via email and LinkedIn to stakeholders in uterine fibroid care took place. One thirty five minute stakeholder was interviewed via phone. Existing implicit bias frameworks were discovered and modified for project use.

Results: There are five domains that recommendations to improve Black uterine fibroid patient outcomes using implicit bias frameworks should operate from: (1) increasing knowledge about the science of fibroids, (2) acknowledging the impact of implicit bias of Black fibroid patient outcomes, (3) creating a safe, non-threatening context & environment to deliver fibroid care, (4) addressing the unique attributes of the Black fibroid patient experience, and (5) implementing sustainable efforts to provide bias-free care.

Conclusions/Recommendations: Public health practitioners should seek to improve diagnosis, management, and treatment of Black uterine fibroid patients by addressing the barriers to care perpetuated by racial biases. Physicians should strive to provide culturally competent quality reproductive care to enhance early detection and expand treatment options for Black patients with fibroids.

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Most importantly, I want to thank the Black women who unknowingly inspired this project with their candidness about their own experiences. I want you to know that your suffering is not in vain and it is not overlooked by me. I see you, I hear you, I love you. It is important to me that we all live a long and healthy life. It is my intention to continue doing work that changes life for us. I hope that I am successful. Because of you, I am.

Table of Contents

Chapter 1: Introduction	1
Background & Significance	1
Problem Statement	2
Purpose	2
Objectives	3
Chapter 2: Literature Review	4
What Are Uterine Fibroids?	4
Treatment Options	4
Their Invisible Burden On Quality of Life	6
Racial Biases Against Black Women	9
How Racism Manifests Around the Black Female Body	10
How Racism Manifests In The Black Female Body	12
Racial Disparities in Uterine Fibroid Management & Reproductive Healthcare	15
Cultural Competence and Humility in Reproductive Health Care	17
Summary	22
Chapter 3: Methods	23
IRB Approval	25
Limitations	25
Chapter 4: Results	26
Increasing knowledge about the science of fibroids	27
Acknowledging the impact of implicit bias on Black fibroid patient outcomes	27
Creating a safe non threatening environment to provide fibroid care	27
Addressing the unique attributes of the Black fibroid patient experience	28
Implementing sustainable efforts to provide bias free care	28
Chapter 5: Discussion, Implications, and Recommendations for Practice	29
Bibliography	32

Chapter 1: Introduction

Background & Significance

Uterine fibroids are common gynecologic tumors. Uterine fibroids are a major source of morbidity for reproductive age women, especially those who identify as African American (Elthouki et. al, 2014). Though uterine fibroids are recognized in about 30% of women of reproductive age, 80% of Black women will develop fibroids (Elthouki et. al, 2014). Even though they experience a higher disease burden with more severe symptoms, access to quality healthcare that educates and empowers them is limited. The lack of access to culturally competent quality reproductive care negatively impacts patient outcomes among Black women. Black women undergo more hysterectomies for fibroids that are potentially treatable by less aggressive procedures than other women. For those who do not have hysterectomies, recurrence is as high as 59% in Black patients who have already received some form of treatment (Al-Hendy et. al, 2017). Black women are subjected to high levels of racial discrimination throughout their lifespan. Racial discrimination is associated with high stress, poor physical and psychological health which negatively impacts their reproductive health (Chinn et. al, 2021). Interventions aimed at raising awareness about implicit bias have been used in efforts to improve health equity for Black patients in other areas of health care (Chinn et. al, 2021). There are many gaps in knowledge regarding fibroids.

This project will illuminate those gaps and ground them in the context of medical practice to improve outcomes of black fibroid patients. By addressing implicit bias, there is an opportunity to reduce barriers to care for Black uterine fibroids patients and increase uptake in services.

Understanding that uterine fibroids are a complex medical problem that disproportionately

impacts Black women, this special project seeks to understand the effect of uterine fibroids in Black women's quality of life, how the absence of cultural competency in patient-provider interactions acts as a barrier to fibroid management, and provides recommendations to improve provider cultural competency and address implicit bias.

Problem Statement

Uterine fibroids disproportionately affect Black women and because of their marginalization, the burdens accompanying the health issue are exacerbated. As an already marginalized group facing numerous health disparities, it is imperative that the field of public health works to address any barriers to care for Black patients and reduce the onset of adverse health outcomes. Fibroids have a negative impact on the quality of life for Black women and often present in their bodies in much more severe ways. Uterine fibroids are often not well managed or treated by their physicians either due to ignorance, bias, or reliance on invasive methods. In addition to being uniquely burdened by fibroids Black women also have more barriers impacting their access to care. The need for action regarding this burden is deep. As many public health organizations begin to understand that racism is a public health crisis, it is vital that the illnesses exacerbated by racism are treated as public health crises.

Purpose

The purpose of this special study project is to create a framework and recommendations to address implicit bias toward Black women seeking reproductive healthcare for uterine fibroids. This framework and recommendations can be used by practicing gynecologists and healthcare facilities to improve patient outcomes.

Objectives

- Identify gaps in knowledge regarding implicit bias and cultural competence in uterine fibroid care focusing on key areas of interest for Black patients
- Engage stakeholders to fill gaps in literature and ground recommendations in context of practice
- Modify existing frameworks for addressing implicit bias in healthcare for uterine fibroid care in Black patients
- Provide recommendations for public health practice that will improve Black fibroid patient outcomes by addressing implicit bias and cultural competence

Chapter 2: Literature Review

What Are Uterine Fibroids?

Uterine fibroids also known as fibromyomas, leiomyomas, and myomas are non-cancerous growths in the uterus that are the most common pelvic tumor. There are four different kinds of fibroids that each have their own symptoms associated with their presence. Three kinds of fibroids grow primarily inside the uterus: intramural, which are the most common, grow on the uterine wall, submucosal, which have the capacity to crowd the uterus, and pedunculated, which can also grow outside uterus on small mushroom like stalks (Fibroids 411, 2018). The fourth kind of fibroid, subserosal, grows on the outside of the uterus and is more painful due to their size and pressure on nearby organs (Fibroids 411, 2018). While some fibroids are asymptomatic and do not reach a size that can cause issues in the reproductive lives of women, the fibroids that are symptomatic and large in size consistently prove to be a health concern (Blount, 2019). The fibroids that occur in Black women are larger with faster growth rates than those in their white counterparts and 20% - 50% have severe symptoms that accompany them (Elthouki et. al, 2014). Some of the most severe symptoms include heavy or prolonged bleeding, passing blood clots, anemia, pain, and cramps which can result in lost work days (Stewart et. al, 2013). These symptoms are difficult to manage without assistance from physicians. Currently, physicians utilize a variety of approaches when identifying treatment options for uterine fibroids.

Treatment Options

Treatment options can be separated into non-removal and removal. Non-removal is characterized by the “wait and see approach”. When utilizing the wait and see approach,

physicians diagnose the fibroids, and then wait to see what symptoms, if any develop. This approach works best in women who either don't have symptoms or have mild symptoms (Fibroids 411, 2018). Drug therapy is an option for those with mild and moderate symptoms. Over the counter pain medications like acetaminophen, ibuprofen, and naproxen help to relieve pain but long term can have side effects on the liver. Oral contraceptives, though not approved by the FDA as a treatment method, can be used to mitigate the symptoms that recur with periods. Gonadotropin-releasing hormone (GnRH) agonists are the most aggressive form of drug therapy and often utilized prior to surgical operations as a means of shrinking fibroids and reducing the risk of bleeding (Fibroids 411, 2018). While an aggressive form of treatment, GnRH agonists are only temporary fixes as the cessation of use allows fibroids to return to their previous size. GnRH can only be used for less than six months due to the many potential side effects such as depression, amenorrhea, and bone thinning (Fibroids 411, 2018).

Removal options are the only forms of "treatment" that can alleviate most of the signs and symptoms associated with uterine fibroids. Recently, non-invasive outpatient procedures have gained traction as the preferred treatment. Endometrial ablation is a minor outpatient surgery that removes the uterine lining to control heavy bleeding (Fibroids 411, 2018). The downside to this procedure is that it makes the possibility of future pregnancy highly unlikely. Hysteroscopic removal requires no incision and destroys fibroids with electricity or laser via a hysteroscope passed through the cervix (Fibroids 411, 2018). Uterine artery embolization is another outpatient procedure where tiny particles are injected to block the blood flow to fibroids and force them to shrink. Laparoscopic Radiofrequency Ablation (Lap-RFA) also attempts to shrink fibroids using heat via a small needle (Fibroids 411, 2018). Fibroid removal options are

often tricky because they may preserve reproductive function but not truly “treat” uterine fibroids. For that reason, doctors tend to encourage surgical options.

There are two kinds of fibroid surgery: myomectomy and hysterectomy. In a myomectomy, the fibroids are removed but the uterus is left intact, which leaves the opportunity for fibroids to develop again in the future (Fibroids 411, 2018). Research shows that this is the case for young women with numerous fibroids at the time of surgery. A hysterectomy is “considered the sure way to cure uterine fibroids” (Fibroids 411, 2018) because it removes the uterus. However most women use this as a last resort because it renders them infertile. Women have described the negative impact that infertility has on their quality of life and anecdotally feel that medical professionals do not acknowledge when creating treatment plans (Dionne, 2020).

Their Invisible Burden On Quality of Life

The impact of uterine fibroids and the symptoms accompanied with the tumors cause a unique level of physical, mental, emotional, and financial strain for Black women (Dionne, 2020). The most current research shows that it is not the existence of fibroids themselves that are the problem for Black women. However, it is the severe symptoms associated with large fibroids that disproportionately burden Black women that impact physical health, mental health, finances, intrapersonal relationships, work performance, fertility, and sex life (Stewart et. al, 2013).

The physical symptoms associated with fibroids underpins many of the other symptoms that impact quality of life. An OB-GYN reported that the patients she encountered experienced mild to severe pelvic pain, heavy periods, painful sex, urinary and or bowel problems (VanNoy et. al, 2020). Heavy periods refers to the increased flow of blood during periods that seeps

through tampons, pads, underwear and clothing. The loss of large amounts of blood can cause one to feel “so weak and depleted that the entire day revolved around drinking Powerade to keep fluids up, taking iron pills, and eating liver” (Dionne, 2020). While the act of bleeding itself can cause health complications like dehydration and anemia, the pain that accompanies the bleeding has been narratively described as problematic. Pain from uterine fibroids can vary from feeling like a “throbbing pain in the lower back that won't subside” (Dionne, 2020) to feeling like very intense menstrual cramps. The pain is debilitating and leaves women relying on painkillers to function. Though most symptoms occur during menstruation, others including painful sex and urinary/bowel problems occur during and outside of menstruation.

Mentally, women can struggle with the experience of having fibroids. Fear, embarrassment, and isolation plague Black women with uterine fibroids. A quantitative study revealed that “many women reported fears associated with their fibroids, including being afraid that the fibroids will grow, that they will need a hysterectomy”, as well as fears regarding relationships, sexual function, body image, loss of control, and hopelessness (Mayo Clinic). Unfortunately, their fears are not misdirected. Uterine fibroids are the leading cause of hysterectomy in the United States and while it may prevent fibroid recurrence, it removes the possibility of having children (Mayo Clinic). Fibroids negatively impact romantic relationships causing painful intercourse (Blount, 2019) making a healthy sex life can become a distant memory for women with symptomatic fibroids. Women fear that issues regarding infertility can prevent romantic relationships from blooming into loving families if they cannot have the children that their partners desire. In platonic relationships, fibroids can act as a barrier to extracurricular activities. An autobiographical account of the experience of living with fibroids revealed that it can make women effectively housebound, isolating them from their support

networks (Dionne, 2020). Under the conditions of pain, heavy bleeding, and mental anguish, everyday tasks like going to work and hanging out with friends may seem virtually impossible. While women may feel more comfortable in their homes where they can manage symptoms without unwanted surveillance, being restricted to their home may impact their ability to maintain interpersonal relationships. Not being able to maintain relationships and meet responsibilities can increase feelings of hopelessness and validate fears regarding relationships and success.

Emotionally, the management of uterine fibroids causes more frustration and hopelessness than the condition. Black women have experiences with physician care that can cause more stress (Dionne, 2020) which creates a feedback loop that only makes fibroids larger and more problematic. Black women who suffer from fibroids often feel like their conditions are not taken seriously by physicians. Despite the fact that fibroids come with a host of symptoms and complications, physicians often attempt to convince Black women that fibroids are common and because they are not cancerous, they are not of urgent concern. (Dillard, 2016) Existing data proves that uterine fibroids, specifically the symptomatic and large in size fibroids, have a negative impact on the quality of life for Black women and often present in their bodies in much more severe ways. Existing data also uncovered that uterine fibroids are often not well managed or treated by their physicians either due to ignorance on the issue, bias, or reliance on invasive methods. In fact, some physicians believe that “because fibroids are not a life threatening condition, it does not have the urgency that many other conditions that affect people do” and that “they are just something you put up with.” (Dionne, 2020). Even though there is no clear cut approach for treating fibroids, Black women feel that physicians can show some regard for their impact on their quality of life during interactions by being more nuanced and discussing fibroids

as potentially harmful not only to a woman's quality of life but also to her reproductive health (Logan et. al, 2021).

To compound the physical and mental burden of fibroids, there is a financial burden that assists in the diminishment of quality of life. In a study conducted by Mayo Clinic, it was discovered that "66% of women were concerned about missed days from work due to their symptoms and 24% of employed respondents felt that symptoms prevented them from reaching their career potential (Mayo Clinic). Missing work or not achieving one's career potential can result in an economic impact. For a disease that is underestimated to cost \$5.9 billion - 34.4 billion annually in the United States and personal accounts that details more than \$1500 dollars in individual costs or co-pays, tests, panties, and medication expenses, having a job is a must when it comes to management. Black women have higher rates of hospitalizations for fibroids, which can be another financial burden. There is a unique difficulty that exists in the lives of Black women with uterine fibroids who's symptoms can be both expensive to manage and obstructive to maintaining employment.

Racial Biases Against Black Women

"What happened on that auction block centuries ago is still unfinished business for African American women today." - Gail E. Wyatt

African ancestry is considered a key risk factor in the development of fibroids (Eltoukhi et. al, 2014). Groups with African ancestry have been subjected to the brutal effects of racial biases against them since the genesis of chattel slavery in the United States of America in the early 1600s. The treatment of Black people, who are single handedly responsible for the generation of the economic power that built the United States, was violent, inhumane, nonconsensual and perpetually destructive. More specifically, the discrimination,

disenfranchisement, and individualized destruction that black women experienced became embedded in American culture and still have repercussions for their health and well being. Racism increases the risk of adverse sexual and reproductive health outcomes for black women.

How Racism Manifests Around the Black Female Body

Structural racism operates within and outside of the health and lives of Black women. (Chinn, Martin, & Redmond, 2021) One of the largest external influences on the health of the Black female body is transgenerational poverty. The disenfranchisement that Black women experienced during slavery and after, dramatically reduced their economic ability in comparison to their non-Black counterparts. By limiting the economic mobility of Black women, racism operates structurally to impact where and how Black women live, work, eat, and heal. This controlled impact results in glaring health disparities that have further disposed a vulnerable population to negative health outcomes.

Where Black women live greatly impacts their options for health care. For example, insurance coverage for fibroid treatment varies by location and in places like the Delta states where there are more black women with fibroids, minimally invasive procedures are not covered by insurance (Fibroids: Why the System Fails Black Women, 2019). Treatment options for fibroids also vary geographically with rural areas having a limited range of treatment options and cities having more providers who are trained in minimally invasive techniques (Fibroids: Why the System Fails Black Women, 2019). Unless women in rural areas can afford to travel to cities or pay out of pocket for minimally invasive treatment where they live, their access to the full spectrum of options is limited. Residential segregation is another function of racism that connects transgenerational poverty with health disparities. Black women live in neighborhoods that have lower property values than their non black counterparts as a result of redlining, which

strategically placed Black people in neighborhoods that the government had disinvested in. Studies have shown that Black people often live in neighborhoods that have been neglected. Food deserts, another result of residential segregation and redlining, limit Black people's access to food sources that would allow the incorporation of fresh fruits and vegetables in their diets. This manifests in Black women having higher rates of obesity which is also a risk factor for uterine fibroids (Blount, 2019). These same neighborhoods often feel unsafe and lack green spaces, discouraging their inhabitants from outdoor activity. Darker skin affects the absorption of Vitamin D, so it is arguably more important for Black people to spend time outside, which their often neighborhoods prevent them from doing. According to the Black Women's Health Imperative, "lower levels of Vitamin D which may contribute to their higher risk of developing fibroids" (Blount, 2019).

While falling ill may not be detrimental to all people, it can be for Black women whom access to healthcare has always been limited. Presently, the United States has one of the most expensive healthcare systems. Health insurance is linked to employment, however because Black women suffer higher rates of unemployment than non-Black women, they are also more likely to not have health insurance. Without health insurance, they are forced to rely on free health care facilities that often do not offer comprehensive services for such intricate conditions like uterine fibroids. In fact, Black people disproportionately rely on public funded clinics for medical treatment because of the costs associated with healthcare (Prather et. al, 2018). This impacts Black women's access to fibroid treatment. During the Civil Rights Era, disparities in health care access and quality were heavily affected by race (Prather et. al, 2018). Black people were forced to use separate health care facilities that were often under-resourced. If they could not be treated in these separate health facilities, their conditions were left to fester. Presently, accessing

fair and timely treatment that aren't accompanied with risks like heart failure, sterility, and where surgery is necessary is not a simple task for Black women (Hutcherson, 2020). While Black women are paid on average \$5,500 less than White women, they are also more likely to be the head of their household than their nonblack counterparts (Loggins et. al, 2018). If they are operating as head of their household, it is safe to assume that their incomes are not solely reserved for their own health care needs. Lack of insurance and or lack of income can operate as huge barriers to seeking healthcare. If Black women are disproportionately affected by these barriers as a function of racism, they are likely limited in their access to healthcare.

How Racism Manifests In The Black Female Body

Racism limited the control that Black women had over their own bodies. With minimal resistance, it was able to manifest inside of the Black female body, quietly but intentionally. During American chattel slavery, Black women specifically bore the dual burden of being both black and women. Due to their enslavement, Black women had little to no control over their own reproductive ability. "Enslaved women often experienced legalized sexual and reproductive exploitation"(Prather et. al, 2018). This sexual and reproductive exploitation has implications for the sexual and reproductive health of Black women presently. Forced reproduction, also known as breeding, was a form of violence that enslaved women were exposed to. "Women who were considered "strong" were sold as breeders and routinely sexually assaulted to birth more children into slavery"(Prather et. al, 2018). The idea that Black women do not feel pain assisted in some of the initial experiments that would underscore the field of gynecology. The field of gynecology is strongly based on non consensual experimentation on Black female bodies. James Marion Sims, also known as the "Father of Modern Gynecology" along with many other physicians,

used enslaved women in experimental reproductive surgeries like cesarean sections, ovariectomy, and other treatments for childbirth illnesses without anesthesia, to perfect these procedures for the use of all women (Prather et. al, 2018). The lack of recognition for pain in Black women still impacts pain management and the speed of prescribing efficient treatment.

Things did not improve for Black women because slavery ended. The Eugenics movement, The Tuskegee Syphilis Study, and Jim Crow laws all occurred after slavery and further exposing Black people to violence that would persist in their bodies for generations. The Eugenics movement coincided with the oppressive Jim Crow laws. In an attempt to control the black population, physicians coerced African American women to undergo sterilizations without providing them with full disclosure or receiving informed consent (Prather et. al, 2018) This forced sterilization was not a new tactic as it displayed the continuation of Black women being restricted from controlling their own reproductive function from slavery. Presently, the maternal mortality rate of Black women is three to four times higher than that of their non-Black counterparts (Chinn et. al, 2021). The Tuskegee Syphilis Study that allowed syphilis to run untreated in Black communities, resulted in heterosexual Black women acquiring syphilis from their male partners and even passing it on to their kids. Presently, Black women suffer a higher burden of STIs than their non-Black counterparts. The Center for Disease Control reports that “African-American women are more likely to be diagnosed with primary or secondary syphilis, gonorrhea or chlamydia. They are also two to three times as likely to have pelvic inflammatory disease, which can lead to infertility or pregnancy complications, than White women (Prather et. al, 2018). The connection between the Tuskegee study and persisting disparities in STIs highlights how effective racism was in causing continuous harm.

Racism manifests in the Black female body as stress. This is problematic as numerous studies have expressed how stress can cause inflammation and negatively impact the body. As black women, lifetime stress is linked to experiences of racial discrimination and childhood sexual abuse (Blount, 2019). Furthermore, Black women are more likely to experience weathering. The weathering hypothesis rests on the idea that there are different levels of stress in built and social environments for Black and white people thus different impacts on their health and well being (Chinn et. al, 2021). Black women experience greater levels of stress than that of Black men and all of their nonblack peers. Some of the stress they experience over the life course begins in the uterus and then compounds through the rest of their life span, increasing their allostatic load (Prather et. al, 2018). Before children are born, racism related stress can impact their well being and result in low birth weight and preterm births (Jones et. al, 2020). Operating from the perspective that this is fact would mean that the stress that Black women experienced as slaves affected the many generations of Black people to come. In fact, perceived stress from chronic experiences of discrimination has been found to be a significant predictor of poor birth outcomes (Chinn et. al, 2021), exemplifying that it is possible to transfer stress from mother to baby. Thus, it can be argued that every Black baby born since slavery has been born with a level of stress present enough to effect their well being.

Despite being the victims of routine sexual assault, the Jezebel stereotype, which painted Black women as hypersexual was a result of this slavery. Other stereotypes that painted them as angry and aggressive furthered racist sentiments (Prather et. al, 2018). Black women utilize different methods to combat stereotypes. One of the most popular methods is a hyperfocus on their appearances with the hope that a polished appearance will project competency to the broader world (Sacks, 2018). They altered their appearance to improve their access to

educational attainment, job opportunities, and relationships in a eurocentric beauty driven world. One way they did this is via beauty products like relaxers, which were used to chemically straighten the hair. The chemicals in these relaxers have since been connected to the onset of severe fibroids (Fibroids: Greater in African-American Women, 2019). This is another example of how racist stereotypes can be particularly harmful to Black women because of their ability to influence behaviors that have unforeseen negative consequences.

Racial Disparities in Uterine Fibroid Management & Reproductive Healthcare

Women will spend the majority of their reproductive years engaging with the healthcare system (Chinn et. al, 2021); thus, quality, comprehensive reproductive health care is important for all women. Black women will also be subjected to high levels of racism and discrimination for the majority of their lifespan. Historically, reproductive care delivered to Black women has not been the most transparent and fair. Practices like compulsory sterilization and neglect of pain management before, during, and after childbirth have limited the reproductive freedom of Black women (Stewart et. al, 2013).

Among racial groups, there are disparities in fibroid discovery, management, and treatment. In order to have their fibroids discovered, Black women need to convince physicians that their pain and discomfort are real. Physicians often ignore the signs and symptoms of uterine fibroids in Black women at early stages of growth because of racial biases that physicians hold against their Black female patients (Hutcherson, 2020). Black women are more likely to visit emergency departments for gynecologic disorders than White women (Chinn et. al, 2021). This is because there is still an issue with access to quality, competent health care for Black women. They struggle with access to more appropriate primary health care services for treatment for

gynecologic disorders in their beginning stages (Chinn et. al, 2021). Perhaps the most disheartening is that Black women “without access to health care or the ability to get medical advice from multiple doctors including specialist” (Dionne, 2020) are often lead away from seeking care, thus default to the wait and see approach, which only gives fibroids more room to grow symptomatic.

The disparities in fibroid treatment reflect the disparities in discovery and management. Doctors hesitancy to acknowledge fibroids is contradicted by their eagerness to surgically treat those same fibroids in their Black patients. Black women report being hesitant that the treatment options they are presented with won't be fertility preserving or that the ones that definitely aren't fertility preserving, will be too invasive. This hesitancy is not far fetched. When prescribing treatment for uterine fibroids tend to defer to more invasive, surgical forms (Hutcherson, 2020). While it is important to recognize that Black women tend to have larger, more complex fibroids, there are additional influences behind the increased likelihood of aggressive procedures. In fact, when hysterectomies are performed “white women and other women with private insurance are more likely to undergo laparoscopic procedures, whereas African American women and women with medicare coverage are more likely to undergo abdominal procedures, even for the same indication (Eltoukhi et. al, 2014). With these more invasive procedures comes longer hospital stays, three times the inhospital mortalities, and other complications like postoperative infections, accidental puncture or laceration, and hemorrhage (Prather et. al, 2018). One of the largest influences behind the default of invasive procedures amongst Black women is lack of information. Black women are less likely to know about the wide range of options when it comes to uterine fibroid treatment (VanNoy et. al, 2020). Thus, they are left to follow the direction of the same physicians who ignored their concerns in the beginning.

Cultural Competence and Humility in Reproductive Health Care

Implicit bias is the mechanism by which providers' actions and decisions are influenced by subconscious thoughts and feelings about certain identity groups. Studies have documented that healthcare providers exhibit unconscious or unintentional bias towards members of marginalized groups, which ultimately leads to differences in treatment (Sacks, 2018). This is relevant for Black women, a marginalized group with a documented history of being stereotyped and overtly discriminated against. In the medical communities, beliefs about Black people having thicker skin and higher pain tolerance than White people exist (Jones et. al, 2020). Relatedly, research shows that physicians are less likely to prescribe opioids to their Black patients who complain of physical pain compared to white patients who make similar complaints. Underestimating symptoms contributes the capacity of physicians to make less accurate treatment recommendations for their Black patients (Jones et. al, 2020). For Black women, there is a constant worry about the impact of negative stereotypes that paint them as poor, uneducated, and hypersexual counters are present in healthcare encounters (Sacks, 2018). This fear causes them to prepare for interactions with their healthcare providers differently, focusing heavily on being very neat in physical appearance, articulate in speech, and informed in conversations about health during visits (Sacks, 2018). However, because implicit bias is not as overt, it is difficult for patients to prepare for and notice. It is ultimately making it the responsibility of the physician to address their own harmful behavior. Implicit bias can show up in physicians as condescending tones, recommending treatment options for patients based on assumptions about what they can handle instead of their true needs (Saluja & Bryant, 2021). Addressing implicit bias is especially relevant for treating Black women with fibroids because biases held against them directly impact the quality of care.

Cultural competence and humility efforts can be used to address the impact of implicit bias on Black women seeking healthcare. The role of culture in everyday life is undeniable. Culture provides a blueprint that affects the way individuals view, experience, and make assumptions about the world. Cultural competence is centered around the “constant learning process that improves awareness, knowledge, and skills of other cultures. Cultural humility is a “lifelong commitment to ongoing self-critique about one’s own implication in patterns of intentional and unintentional advantage and disadvantage by ethnicity, race, class, gender, and sexual identity” (Beagan, 2018). It requires people to look beyond themselves and understand that some of the differences in cultures are a result of harm. Having competence and humility for all cultures is especially important in healthcare because, “Culture specifies the care available to the family.”(Etowa & Adongo, 2007). Not only is this cultural humility and competence beneficial to patients, but it is also beneficial to institutions. According to a study done on cultural competency in hospitals, “CEOs believe embracing cultural competence efforts helps them achieve the organization’s mission and priorities as well as meet the needs of a particular population.”(Wilson-Stronks & Mutha, 2010). Despite the mutual benefits of cultural competence and humility for patients and providers, health care settings are not places that feel welcoming to marginalized ethnic groups like Black women due to the lack of culture competency. For Black women seeking health care, cultural competency is of particular importance because they are “exceptionally vulnerable during health care encounters due to sociocultural barriers” (Logan et. al, 2021). Given the amount of health disparities in reproductive health care, it is important for physicians to display a level of cultural competence and humility that encourages their patients to utilize their agency while prioritizing their well-being.

Patient provider interactions are the cornerstone of health care treatments and interventions. In these interactions, patients typically access information about their conditions, recommendations for management, and options for treatments. For Black women with fibroids, access to medically accurate information is important for management and treatment. They often receive little to no information from their parents about sexual and reproductive health (Logan et al, 2021). Culturally, Black parents do not feel that talking sex with their children is appropriate or necessary (Logan et al, 2021). They sometimes believe that it will encourage their children to have sex or that they can get the information elsewhere. It is important that physicians address any misinformation that Black women report limited communication about sex in their families and communities (Logan et al, 2021). Taking into account the historical roots of physician mistrust between Black patients and white physicians, how interactions look between patients and doctors matter a lot for patient comfort. Prior studies show that there is a need for improved dialogue between Black patients and clinicians (VanNoy et al, 2020). Thus, it can be argued that Black women do not feel comfortable with their health care providers and as a result may withhold information or give minimal information. Their dialogue is not always an exchange where both parties actively listen and respond. Truthfully, physicians are more likely to underestimate and undertreat Black women compared to non-Black women, leaving Black women feeling dismissed (VanNoy et al, 2020). This behavior is harmful as it reinforces the lack of confidence that Black women have in the healthcare system to treat them thoroughly, accurately, and fairly. Though the trust for physicians and their intentions is not high among Black women, they still rely on them for medically accurate information. Physician mistrust among Black people is a very serious issue in healthcare that often results in a decreased uptake of healthcare services. Cultural competency can work to address physician mistrust by

establishing the understanding in physicians that the legacy between them and their Black patients is in the room with them during their interactions as well. The mutual understanding can signal to providers that special attention and detail is needed to adequately address the concerns of their Black patients.

The components of health care settings can increase or decrease patient comfort in vulnerable environments such as gynecologist offices. Colorblindness is not helpful in healthcare. It is important that Black patients see themselves represented at the facilities where they seek care. This means having Black doctors, nurses, ultrasound technicians, pharmacists, and other healthcare staff on care teams is important. Having a staff that adequately represents the patients is not just beneficial for the patients. “Cultural representation among staff in the health care setting not only provides reassurance to the clients but serves as a readily available information source to health care professionals as well” (Etoowo & Adongo, 2007). Implicit biases are held by everyone. Having more Black staff can be a source of unlearning that occurs before a negative patient interaction discourages Black women from seeking care. Some women shared that past experiences with same race providers were markedly different from health care experiences with racially and ethnically discordant providers” (Logan et. al, 2021). It should be stated, not implied that the difference was one that worked for the benefit of the patient, resulting in them feeling more validated, cared for, and seen than in previous interactions.

For Black women, dealing with fibroids is often an isolating experience. Though 80% of all Black women are impacted by fibroids, those who are burdened with uterine fibroids feel embarrassed and do not believe they can talk to their families about the experience. In a firsthand account from a Black woman with fibroids, she states that “the shame kept me silent for long” (Dionne, 2020). Patient provider communication, community norms, and social structures

influence fibroid management choices. All of these factors are influenced by culture. A study on fibroid management choices found that “the fibroid management decisions of Black women were shaped by individual interactions with clinicians and social networks, and concerns about fibroid health consequences” (VanNoy et. al, 2020). For Black women, sufficient dialogue about treatment options and alternative treatment options are extremely important. Physicians are believed to have access to this information and be able to engage in this dialogue. However, their ability to influence fibroid management decisions is limited because there is a “particular lack of knowledge about the development of fibroids and how to treat them.”(Dionne, 2020).

Physician-patient conversation should also provide more time to consider potential treatment options rather than waiting until the fibroid symptoms require immediate action (Dillard, 2016).

While cultural competence and humility in reproductive health care may not reduce the onset of uterine fibroids in Black women, it can improve the experience of managing and treating them.

There are some limitations with cultural competence and humility models. One of the biggest limitations of cultural competency is the impact of change and fluidity on culture. Cultures change at a pace that individual people cannot always replicate (Beagan, 2018). Furthermore, all humans are still individuals with individual agency. Not treating people as individuals can further generalizations made about groups (Beagan, 2018) and work against the process of cultural competence and humility. Another limitation is the complexity of human nature. While exposure to diversity is assumed to be helpful in combating implicit biases, it can be met with resistance. Some people become less comfortable and confident learning about diversity and practicing humility (Beagan, 2018) because it forces them to examine their own biases and assumptions about people in the world who have suffered differently or greater than

them because of their identities. This unwillingness can impact the efficacy of cultural competence and humility efforts, including trainings and programs.

Summary

Uterine fibroids disproportionately burdens Black women and their quality of life. In order to inform the development of a framework and recommendations for physicians who treat Black women with uterine fibroids, this literature review explores the circumstances of Black women suffering from fibroids. The legacy of racism toward Black women manifests in and around their bodies to generate a host of negative health outcomes. The intersection between the impact of racism, quality of life, and the lack of cultural competency in reproductive health care creates a scenario where Black women continue to suffer from fibroids with limited avenues for reprieve. In order to reduce disparities in fibroid discovery, management, and treatment, health care providers need to understand the forces behind the disparities. Incorporating a level of cultural competence and humility in reproductive health care settings can enhance Black women's healthcare experiences with physicians and increase their uptake of non-emergent health care services.

Chapter 3: Methods

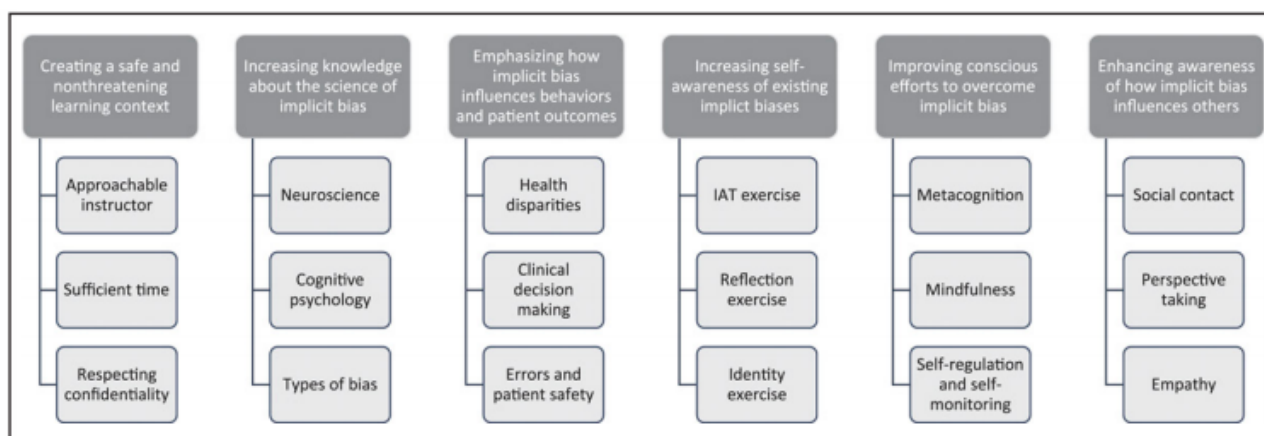
Methods

The purpose of this special study project was to make recommendations for improving uterine fibroid care and management to address the disproportionate burden that Black women experience with the condition.

The project began by conducting an extensive literature review. The purpose of the literature review was to gain a full understanding of what fibroids were scientifically, the impact on Black women's quality of life, examine the root causes of the disparity and establish a backing for recommendations to address the disparity. I began with a general search on PubMed using the terms "fibroids" and "black women". This expanded into an advanced MeSH (Medical Subject Headings) search using the medical term for fibroids "leiomyoma" and "African American or Black" instead of just Black women. This produced 343 results. Using some of the articles that the MeSH search produced, I then applied a snowball strategy using the cited articles. I used the Web of Science and Women's Studies International databases, which produced 42 results.

Google Scholar was used to find literature regarding the black experience in healthcare generally, cultural competence research, and Black women's history. While this database produced upward of 50,000 results per search, when adding the word fibroid, results were slim to none. Therefore, it was more appropriate to use it for the more general topic areas of the project. Next, I engaged stakeholders to inform some of the concepts discovered in the literature and enhance my understanding of the clinical applicability and utility of the proposed framework and recommendations. I began by creating a stakeholder interview guide aligned with the topics covered in the literature review. This stakeholder interview guide was adapted into a survey using Google Forms (Appendix 1). Topics of the survey included: Fibroid Treatment and

Management, Perceived Role of Race, and Recommendations. I used various strategies to recruit stakeholders. I used social media sites, namely LinkedIn, Facebook Groups, and Twitter to recruit people who had experience treating fibroids or having their own fibroids treated. I disseminated the survey questionnaire in Uterine Fibroid related Facebook Groups. Then I emailed different fibroid specialists in the Atlanta, Georgia area attaching the survey. Then I reached out to current practicing OB/GYNs via LinkedIn and email with the option to respond to the survey or respond during an informal 30 minute stakeholder interview. Though many methods of recruitment were used, only two respondents engaged and of those two, one agreed to participate in a 30 minute phone based stakeholder interview using the survey questions as a guide. Using the findings from the literature and the stakeholder interview findings, I adapted an existing implicit bias framework (Sukhera & Watling, 2018) for health professionals to be relevant for uterine fibroid care. Figure 1 shows this foundational implicit bias framework.



IAT = implicit association test.

Figure 1. Framework for integrating implicit bias awareness and management into health professional education (Sukhera & Watling, 2018)

The new adapted framework (Figure 2) was created as a means to organize results and recommendations for practice.

IRB Approval

IRB approval was waived for this project because it was a special studies project that did not involve human subjects with no intent to generalize for the broader population.

Limitations

Due to the busy schedules of practicing OB/GYNs which were exacerbated by the COVID-19 pandemic, stakeholder engagement was lower than desired. This does not take away from the merit of the project as the stakeholders purpose was to provide context about the literature in practice and offer recommendations of their own. However, it does limit the variety of perspective outside of the literature. Never-the-less, the existing lack of literature on implicit bias in fibroid care demonstrates that this special project is beginning to fill a large gap in the literature.

Chapter 4: Results

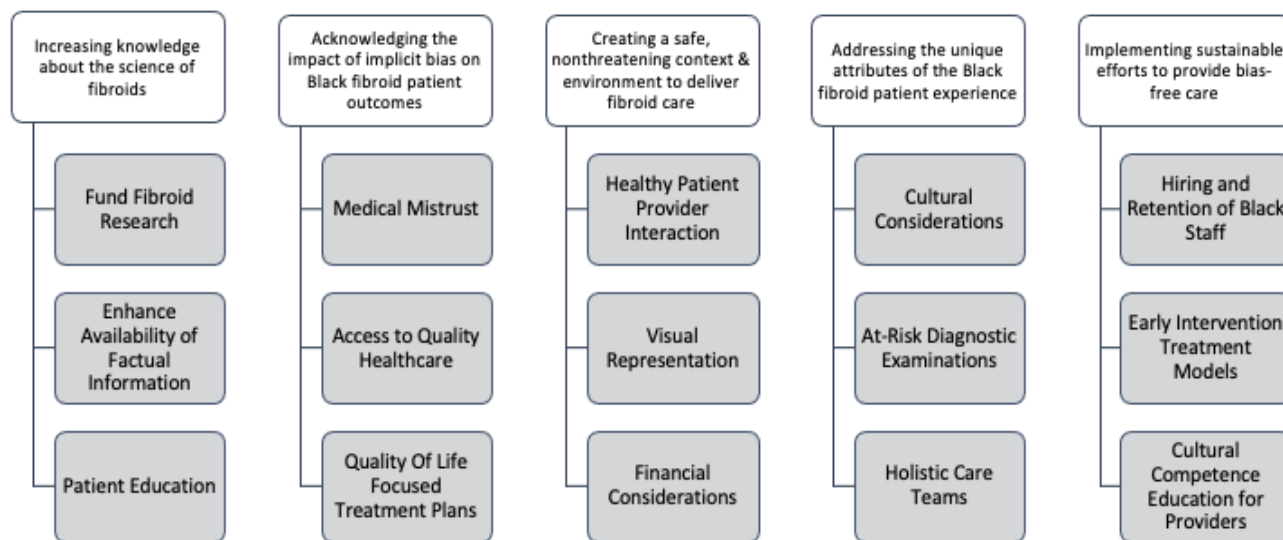


Figure 2. Framework for addressing implicit bias and improving cultural competence Black fibroid patients

The disproportionate burden of uterine fibroids on Black women can be addressed by increasing knowledge about uterine fibroids and the aspects of the experience that are unique to Black women, processing that knowledge, then implementing it to practice in a sustainable way. The framework in Figure 1 was adapted to reflect the five domains by which providers address implicit bias and reduce barriers to uterine fibroid management for Black women. Figure 2 shows the proposed framework around which recommendations will be organized. The domains were reduced from five to six because the sixth domain “increasing self awareness of existing implicit biases” was out of scope for this project’s aims. During research, this domain proved to be most challenging and demonstrated potential to be a barrier to affecting change at a meso level due to its individual focus. However, as with all implicit bias training, critical self-reflection would be a required step.

Increasing knowledge about the science of fibroids

This domain addresses the availability of factual information which was identified as a barrier for both patient and provider. Fibroids are seen as a nuanced topic in reproductive healthcare (Eltoukhi et. al, 2013). There is still uncertainty about what causes fibroids and how to prevent them if they are preventable (Eltoukhi et al, 2013). Diagnosis cannot occur before symptoms arise. Treatment options vary but often do not prioritize quality of life. Funding fibroid research could help to identify avenues of prevention, improve diagnostic techniques, and expand treatments. With the enhanced availability of factual information, physicians have the opportunity to address myths and educate their patients.

Acknowledging the impact of implicit bias on Black fibroid patient outcomes

Implicit bias contributes to the disparity of fibroid patient outcomes by exacerbating mistrust and inhibiting access to health care that prioritizes quality of life (Sacks, 2018). Medical mistrust has an impact on the uptake of services among Black fibroid patients by operating as a barrier to seeking treatment. Access to quality reproductive healthcare that directly addresses patient needs without minimizing or underestimating symptoms is limited for Black women. The biases that physicians have against Black women impacts the accuracy of their treatment plans (Jones et. al, 2020). Treatment plans for Black fibroid patients do not currently account for the way that infertility negatively impacts quality of life within Black culture (Dillard, 2016).

Creating a safe non threatening environment to provide fibroid care

The environment in which fibroid care is delivered needs to be safe and non threatening so that patients can feel comfortable stating their needs and having their needs met. The creation of a safe non-threatening environment is the responsibility of the health care provider (Saluja &

Bryant, 2021). Healthy patient-provider interaction, visual representation of marginalized groups, and financial consideration contribute to the creation of a non-threatening environment where patients can feel comfortable seeking care.

Addressing the unique attributes of the Black fibroid patient experience

Culture is a large influence on reproductive health behaviors in Black female patients (VanNoy et. al, 2020). Considering cultural aspects when delivering patient education and treatment plans increases effectiveness (Dillard, 2016). Given that Black women are at a higher risk for developing fibroids than other women, frequent diagnostic examinations are helpful for treating fibroids before they become symptomatic. Black fibroid patients experience physical, emotional, mental, and financial setbacks. Centering the tumors' impact in their lives can allow for the creation of treatment plans that adequately address all health concerns and enhance patient well-being.

Implementing sustainable efforts to provide bias free care

Implementing sustainable actions that support the provision of bias free care is critical. Hiring and retaining Black staff has benefits for improving workplace diversity and increasing comfort in treatment for Black patients (Etowo & Adongo, 2007). Enhancing healthcare providers' cultural competence can be helpful for all patients, providers, and the facility. Enhanced cultural competence allows patients to receive accommodations directly related to their specific needs which assists with patient adherence to provider treatment plans and reduces costs for facilities (Wilson-Stronks & Mutha, 2010). Cultural competency and implicit bias training should be delivered continuously and treated as an iterative process.

Chapter 5: Discussion, Implications, and Recommendations for Practice

This project revealed unmet needs regarding knowledge, safety, and comfort of Black uterine fibroid patients seeking medical care. Many of the unmet needs among Black fibroid patients are a result of historic overt and covert racism. Therefore, the use of implicit bias awareness frameworks that prevent the perpetuation of bias and increase intercultural dialogue is appropriate. There are numerous opportunities for pointed intervention by public health practitioners. The burden of uterine fibroids in Black patients is a public health issue in need of attention. This project provides the field of public health with actionable steps to begin the process of improving Black fibroid patient outcomes.

The lack of adequate knowledge about the science of uterine fibroids uniquely affects Black patients. Lack of knowledge keeps Black women living in shame and listening to myths about their reproductive health. To meet the need for more knowledge, more funding for uterine fibroid research with a focus on Black women should be conducted. Black women should be involved in the entire research design and procedures in order to manage feelings of mistrust. Increasing research will enhance the availability of factual information for providers. Providers should then share that information with patients during visits. The increase in factual information can also be used to deliver culturally appropriate community based outreach and education. Patients should be educated so that they feel empowered to make decisions regarding their own care. Providers should take the time to make sure their patients understand their conditions with an emphasis on the full range of options for management and treatment.

There needs to be acknowledgement by public health practitioners and providers of the impact of implicit bias on patient outcomes in Black women with uterine fibroids. There is a well-documented history of injustice toward Black people seeking medical assistance generated

which has resulted in a persistent level of mistrust for Black patients. Efforts focusing on building trust in medicine among Black fibroid patients is vital to the effectiveness of treatment plans. Black fibroid patients express that their quality of life is negatively impacted by the presence of fibroids. Providers should take that into consideration when creating treatment plans. This could be done by creating treatment plans where fertility is preserved.

The need for a safe and non threatening environment to deliver fibroid care is directly related to the expressed vulnerability and fear that Black fibroid patients have. Given that patient- provider interactions are narratively stressful for Black patients, interactions where they feel empowered and informed can positively influence their patient experience. Providers should take more time with their Black patients. This will allow them to listen to their patients' concerns fully, examine body language and address them adequately. Facilities should take the steps to ensure that pamphlets, posters, and magazines in waiting rooms resonate with their patient population. Visual representation of patient identities aid in the creation of a comfortable environment. Financial barriers prevent Black women from accessing uterine fibroid care. Facilities that want to overcome this barrier can introduce a sliding scale payment option for the insured and uninsured. This would increase the opportunity for Black women to seek high quality reproductive healthcare without financial burden.

The unique experience of Black women with uterine fibroids requires a unique approach in the provision of care. Given that culture impacts the health behaviors of Black women, elements of Black culture should be considered. While the idea of specializing care for one particular population is not a novel concept in healthcare, it has not yet occurred in fibroid care. The only way to discover fibroids is to feel them in the uterus during physical exams. Black women are an at risk population for uterine fibroids that grow at faster rates, therefore they

should have diagnostic physical exams more frequently. Instead of only being done once a year during annual exams, checking more frequently would allow for early detection and intervention. The experience of having uterine fibroids is not purely physical. Therefore, the treatment team and plan should not only focus on the physical aspect. Holistic care teams that address the emotional, mental, and physical burden deliver well rounded care.

Finally, a sustainable implementation of conscious efforts at reducing bias. Hiring Black staff is one attempt to address implicit bias. However, continuing education regarding bias and cultural competence is equally important. Cultural competence training has proved to be beneficial across the board in healthcare. It should be mandatory that providers engage in continuous training, implementation and practice. Providers should also be evaluated on their ability to practice cultural competence with their patients and deliver bias free care. Healthcare facilities should take active steps to ensure that the work environment is conducive to their Black physicians, nurses, and recognize that all staff bring their whole selves to the workplace. Early intervention is vital to delaying the onset of symptoms associated with uterine fibroids. Research shows that the fibroids that Black patients typically experience grow larger, faster, and are severely symptomatic. Therefore, the wait and see approach that physicians use when treating uterine fibroids should not be used with Black uterine fibroid patients. Physicians should utilize early intervention treatment models that prioritize proactive measures as a means of circumventing negative impact on their Black patients quality of life.

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