

Black Women's Psychosocial Experiences with Seeking Surgical Treatment for Uterine Fibroids: Implications for Clinical Practice

Brianna N VanNoy

George Washington University https://orcid.org/0000-0002-0059-6268

Lisa Bowleg

George Washington University

Cherie Marfori

George Washington University School of Medicine

Gaby Moawad

George Washington University School of Medicine

Ami R. Zota (■ azota@gwu.edu)

https://orcid.org/0000-0003-0710-354X

Research article

Keywords: Uterine fibroids, qualitative research, health disparities, Black women

Posted Date: March 3rd, 2020

DOI: https://doi.org/10.21203/rs.3.rs-15726/v1

License: © 1 This work is licensed under a Creative Commons Attribution 4.0 International License.

Read Full License

Version of Record: A version of this preprint was published at Women's Health Issues on May 1st, 2021. See the published version at https://doi.org/10.1016/j.whi.2021.01.001.

Abstract

Background Black women are disproportionately impacted by uterine fibroids and are more likely to undergo surgical treatment for fibroids compared with non-Black women. However, few studies have characterized the psychosocial experiences of Black women seeking treatment for fibroids. This study aimed to identify factors that shape Black women's fibroid management decisions; explore how discrimination based on race, class, and gender feature in treatment-seeking experiences; and compare experiences by age and socioeconomic status (SES). Methods We conducted semi-structured interviews with 37 Black premenopausal women, undergoing either a hysterectomy or myomectomy for fibroids at an academic medical center. We used a thematic analysis to code transcripts and identify themes. Results Participants were predominately single, highly educated, and privately insured. Respondents reported that patient-doctor interactions, support from social networks, fertility consequences, and fear of fibroid malignancy influenced their fibroid management decisions. Their knowledge and perceptions of fibroids were also influenced by social and community norms and differed by SES; women of higher SES had greater fibroid awareness than women of lower SES. Discrimination was discussed in the context of historical inequity against Black women, with one participant questioning whether Black women were valued less in clinical settings compared with non-Black women. While several women discussed positive experiences seeking fibroids care, others expressed medical mistrust or said that alternative management options were not offered by clinicians. Conclusions Fibroid management decisions were influenced not only by individual-level interactions with clinicians and social networks, and concerns about fertility and fibroid malignancy, but also by broader social and historical conditions. These findings suggest that clinicians should deliver culturally-competent gynecologic care that centers the voices of Black women and acknowledges the diverse perspectives and perceptions that Black women may have when seeking fibroid treatment.

Background

Uterine leiomyomas (fibroids) are non-cancerous, smooth muscle tumors in the uterus that develop in nearly all reproductive-aged women in the United States.^{1,2} Black women are disproportionately impacted by fibroids, often experiencing an earlier age of onset and more severe morbidity.^{1,3} Although hysterectomy is the least preferred procedure for fibroid treatment by women regardless of fertility intentions,⁴ and Black women are generally more opposed to surgical management compared with non-Black women,⁵ Black women are still more likely to undergo surgery for fibroids.³

Little is known about the factors that drive fibroid management decisions from the patient perspective, or how these factors may differ across and within racial/ethnic groups. A few studies have evaluated associations between patient characteristics and treatment procedures, 6,7 however, they did not capture the psychosocial context within which women make management decisions. Furthermore, prior studies did not examine how patient-provider communication, community norms, or social structures (e.g., institutional discrimination) influence management choices. These factors are important given the

growing body of social science research that suggests experiences in healthcare settings extend beyond individual-level interactions, and are also shaped by intersecting social conditions.^{8–10}

To address these empirical gaps, we conducted a qualitative study among Black women undergoing either myomectomy or hysterectomy for fibroid management. We investigated three research questions: (a) what are the factors that influence Black women's fibroid management decisions, (b) how do issues of discrimination by race, sex, and class manifest in their treatment-seeking experiences, and (c) how do Black women's experiences vary by age and socioeconomic status.

Methods

Study Population. We recruited women into a clinical epidemiologic study on uterine fibroids from 2014-2017 at a medium-sized, urban university medical center in the Washington D.C. metropolitan area. Eligible women were English speaking, premenopausal, non-pregnant, ≥ 18 years of age, and undergoing either myomectomy or hysterectomy at a specialty surgical clinic for fibroid management. Of the 68 women approached about the study, 90% consented to participate (n = 61). The appropriate sample size in qualitative studies is generally guided by the principle of "saturation," or the point at which no new themes or findings are noted. 11 Estimating sample size depends on various factors including the study design and quality of the data, and can include as few as 6-10 participants. 12 Based on these factors, we estimated that a sample size of at least 30 participants would be sufficient to obtain rich contextual data on Black women's experiences seeking fibroid treatment using qualitative methods. 12 Our sample consists of 37 self-identified Black/African American women who completed the qualitative interview component of the study. The mean age of our sample was 38.8 years (range 26-53), and approximately half of the women were nulliparous. The majority of participants were single, privately insured, had at least a college degree, and were undergoing hysterectomy (Table 1). Information about fibroid burden (e.g., number of fibroids, uterine volume) has been characterized by our study team and is published elsewhere. 13

Table 1

Demographic Characteristics of Black Interview Participants (N = 37)

Characteristic Characteristics of Bia	N (%)
Age (years)	
26-32	8 (21.6)
33-44	19 (51.4)
45-53	10 (27.0)
Relationship status	
Single	28 (75.7)
Married	3 (8.1)
Divorced	5 (13.5)
Unknown	1 (2.7)
Parity	
0	18 (48.7)
1	9 (24.3)
≥2	10 (27.0)
Insurance type	
Private	22 (59.5)
Public	11 (29.7)
Government/military	4 (10.8)
Education level	
Graduate degree	13 (35.1)
College graduate	8 (21.6)
Some college	11 (29.7)
High school diploma	4 (10.8)
9th grade or less	1 (2.7)
Surgical Procedure *	
Hysterectomy	20 (55.6)

^{*}One participant did not follow through with surgery but was intending to have a myomectomy at the time of the interview.

Characteristic	N (%)
Myomectomy	16 (44.4)

^{*}One participant did not follow through with surgery but was intending to have a myomectomy at the time of the interview.

Procedures. Because participants were enrolled in the study over three consecutive years, we chose a semi-structured interview approach to minimize variation in the questions posed to interviewees, and ensure that data obtained for each participant were systematic. 14 Trained female research assistants (3) Black, 1 Latina, 1 White) conducted interviews either over the phone or in a private space at the medical center, and utilized a semi-structured interview guide to elicit conversation about pertinent topics while allowing flexibility for patients to share their experiences. 14 The open-ended interview guide included questions about women's experiences with receiving a fibroids diagnosis, their perceptions about risks associated with fibroids, their interactions with clinicians for fibroids diagnosis and care, and the influence of their social networks on fibroid management decisions. Sample interview questions included: "How did you discover you had fibroids?"; "Were you aware of fibroids as a risk before you learned you had it?"; "How has their (clinicians) advice worked for you?" and "Are there ways that you get support from friends and family about your condition?" The average length of each interview was 11.28 minutes (range 2.53–25.49). We also administered a standardized questionnaire to obtain demographic information such as educational attainment, and reviewed participant medical records to confirm age, menopausal status, insurance coverage, and presence of fibroids. All women provided written informed consent prior to being interviewed. The study was approved by the Institutional Review Board at the George Washington University.

Data Analysis. Interviews were audio-recorded and transcribed verbatim with original recordings preserved for reference. In most cases, interviews were transcribed by the research assistant who conducted the interview to ensure that transcribed interviews were consistent with recalled conversations. All audio-recorded interviews and transcripts were independently reviewed once more by two research assistants for quality assurance.

We conducted a thematic analysis to develop codes and identify themes. Thematic analysis is a strategy used to identify, analyze, interpret, and report patterns in qualitative data. The first author thoroughly read the transcripts at least twice to become familiar with the data. Guided by the research questions, we developed a preliminary codebook with initial codes (e.g., patient-doctor communication, race) and documented theoretical and reflective thoughts for each transcript. We then imported complete transcripts into NVivo 10 (QSR International), a qualitative data management software. The first author individually coded each transcript line-by-line, guided by the preliminary codebook and the research questions. Additional codes (e.g., patient expectations, what is normal) were developed using an inductive, iterative approach. We reviewed and refined coded transcripts, and recoded all transcripts using the final codebook, which consisted of both the a priori codes relevant to the research questions and

emergent codes. To assess differences in experiences across age (< 40 years vs. ≥ 40 years of age), education level (at least a college degree vs. less than a college degree), and insurance status (private insurance vs. other), we utilized the attribute feature in NVivo 10, a tool that classifies transcripts based on specific variables. We then exported the attribute data and manually evaluated differences in participant accounts using Microsoft Excel. Themes identified during the coding process, and after coding was complete were reviewed for relevance to the research questions. We consistently referenced the transcripts to ensure that participant accounts supported the conclusions drawn. The study authors collaboratively discussed themes until consensus was reached.

Trustworthiness of analyses. We used four criteria to assess the quality of our analyses: prolonged engagement with the data, credibility, transferability, and confirmability. ¹⁶ First, prolonged engagement involves spending sufficient time with the data. To demonstrate this, we read the transcripts multiple times, reviewed and revised codes, and compared the transcripts, codes, and our interpretations through an iterative approach. Second, we evaluated the credibility of our findings by examining the extent to which our interpretations were rooted in the data. The findings of a qualitative study may be transferable if the conclusions drawn can be compared with other samples or theories. We have provided "thick description" of our findings, including detailed information about the sample, to assist others in assessing transferability. ^{17,18} Lastly, to assess confirmability, we have provided a detailed description of our procedures and analyses, and have included illustrative quotes from participants in the results section to support the conclusions drawn. All quotes are written verbatim, except for minor edits to improve clarity. To protect the confidentiality of participants, we have provided pseudonyms with the age and procedure type (hysterectomy "H" or myomectomy "M") in parentheses, and changed or omitted other identifiers. The results presented reference the accounts of all 37 Black women.

Results

Participants provided detailed accounts of their experiences seeking treatment for uterine fibroids. We present our findings relevant to the research questions about the factors that influence Black women's fibroid treatment decisions, experiences of discrimination in healthcare settings, and differences by selected variables. Guided by the research questions, we have organized the findings around four key themes identified in the analysis: 1) patient-doctor interactions, 2) the social and historical value of the uterus, 3) fertility consequences and fear of malignancy, and 4) the role of community.

Patient-doctor Interactions

Fibroids diagnosis experience. All of the women in our study (N = 37) discussed their fibroid diagnosis experiences, with women discovering fibroids through routine gynecologic visits (n = 28), emergency room encounters for severe pain or bleeding (n = 6), or incidentally during pregnancy (n = 3). For six women, poor patient-doctor interactions were a barrier to receiving a fibroids diagnosis. Women described how their clinicians initially dismissed symptoms (n = 3), or wrongly attributed symptoms to other issues (e.g.,

weight gain, postpartum recovery) without further investigation (n = 3). Typical was Kierra (age 37, H) who recalled that her clinician silenced her concerns saying, "Oh, you're fine" in response to complaints about heavy bleeding. Lauren (age 42, M), who had been complaining about fibroid-related symptoms for several years, shared how her clinician attributed her symptoms to weight gain and advised a diet and exercise program. Lacking a definitive diagnosis and management plan that could alleviate her symptoms, Nina (age 38, H) grew frustrated, recalling how the process nearly led her to give up:

I kind of got frustrated because...it felt like the same speech every time I went. I did about six visits in a row trying to figure out [the problem]...it felt like a little run around to the point where I just said, "Forget it. I'm just gonna...deal with the pain."

Several participants (n = 7) expressed relatively low perceptions of risk for fibroids because during the initial diagnosis, clinicians had advised them "not to worry." Typical was Ashanti (age 51, H), who was first diagnosed with fibroids in her 20 s. She recounted that "I was so young then, so I don't recall them telling me it was a risk...the doctor explained that most women had fibroids or something and that mine were so small that it was nothing to even be alarmed about." Although fibroid severity can progress over time, awareness about potential disease progression at the time of diagnosis was not clear for women like Camela (age 30, M), who expressed confusion about a clinician's change in management advice after her initial diagnosis:

I was told [by the doctor] not [to] worry, and I was not worrying about it, but I knew something was wrong. But he's the doctor, he's supposed to know what to do, I mean I'm supposed to listen... As the years go by, my stomach is getting bigger, and I'm like okay, you said this but what is going on?

Patient expectations for clinicians. After receiving a fibroids diagnosis, respondents expressed diverse expectations for clinicians in seeking care for fibroids. Four women explicitly expressed the desire for clinicians to provide a range of fibroid management options including non-surgical options. For example, Pamela (age 45, H) shared her perspective on the treatment options offered:

...it [hysterectomy] seemed like the only option, they didn't have any other medical procedures that could either stop their growth...[or] maybe, lessen their growth, or just remove just the part [of the fibroid]. You know, like, those solutions weren't offered.

It is unclear whether participants thought that clinicians were concealing additional options or whether they believed that management options were limited overall, but in general, women expected more information from clinicians about fibroids, and were frustrated with the lack of information provided. Jada (age 32, M), recounted that she expected her clinician to provide advice on lifestyle modifications or preventative steps: "I wanted to get more information, but she didn't tell me to stay away from anything or do something... [to change] my lifestyle... She was like "Oh you'll just need surgery." Along the same lines, Catherine (age 32, M) mentioned, "I don't think that I'm really getting advice that I didn't already see on the Internet," suggesting that she hoped to receive specialized information that she could not readily access elsewhere. To reconcile with this lack of information, 10 women discussed how they sought second, and

sometimes, third opinions from new clinicians. For example, after receiving limited information from her first clinician, Halle (age 36, M) "immediately got another doctor who...explained it a little bit more and was a little bit more educational in answering [her] questions about [fibroids]." Consistent with Jada, who "just read what [she] needed on [her] own," 14 other women discussed how they gathered information about fibroids from online sources, family and friends, and support groups to help make informed decisions about treatment.

The Social And Historical Value Of The Uterus

Women shared diverse perspectives and responses regarding fibroid management options. Thirteen women reported that their clinicians initially recommended pain medications or hormonal contraception to manage symptoms. Four out of the 13 women, however, may have perceived medication as a temporary fix, stating that they were not interested in taking pain medication or birth control pills. As Tyra (age 38, M) detailed, she did not want to "just keep popping pills for the pain." Seven participants described hysterectomy, the first option that some clinicians offered, as a recommendation that elicited mixed reactions. Three out of the seven women expressed neutral or positive feelings about undergoing hysterectomy, while four women reacted negatively to the recommendation. Halle (age 36, M) felt a lack of empathy from her gynecologist when discussing hysterectomy with her: "Her first, initial reaction was I needed a hysterectomy. And that, you know, I'd never be able to have children... [She] told me these things and I panicked, I was anxious, I was slightly depressed probably." Lauren, on the other hand, was skeptical of her clinician's recommendation for hysterectomy, and questioned whether the recommendation was out of the physician's convenience:

...because everyone I've talked to has that same feeling of like, "Why was the first thing that you recommended to me a hysterectomy? I get I'm not married, I get I have no children. Why was that the first thing you recommended? Was that to make your life easier? Why won't you try to preserve who I am as a person?

These negative reactions may have been informed by a historical legacy of discrimination and devaluation that is explicitly or implicitly expressed in contemporary healthcare settings, and that fosters medical mistrust or skepticism.¹⁹ Indeed, intersecting issues of systemic racism and sexism, rooted in decades of slavery, oppressive Jim Crow laws, and the historical violation of Black women's bodies (e.g., forced sterilizations, medical experimentation) may affect the daily lives of Black women in the U.S.²⁰ Lauren, who spoke candidly with her family and friends about fibroids, echoed the impact of this historical legacy in her account, and questioned whether clinicians targeted Black women for hysterectomy compared with non-Black women:

The only [women] who told me... to find other doctors, were the [women] who were told [by clinicians] to have a hysterectomy...and [they] were like, "No, I don't want that. I want to keep my uterus." It was interesting in the sense that all of them were Black women. And so, we all did not know whether there was

a concept of our uterus isn't valued because we're Black women, is it because we're not valuable as Black women?

Fertility Consequences And Fear Of Malignancy

Fertility consequences. Women expressed additional health and wellness concerns that influenced their decisions regarding surgical treatment. The most discussed concern was fertility (n = 15), particularly for women younger than 40 (n = 10). Concerns about fertility were often coupled with the discontent of hysterectomy as a treatment option, with younger women (< 40 years) being more opposed to hysterectomy compared to older women (≥ 40 years). For example, Diana (age 29, M) recounted her response to the treatment options offered stating, "My choices I was told [were] like, 'hysterectomy, hysterectomy, just take all [of] it out!' But nah, I think everybody deserves to have a kid someday." On the other hand, Cathy (age 53, H) discussed how she was content with undergoing a hysterectomy because she did not "intend to have more kids," but acknowledged, "Most people are concerned about [childbearing] when they're younger." There was one exception to this trend, however; Alexa (age 37, H) discussed how, despite her fertility intentions, "no other solution really gave [her] the satisfaction [she] wanted at the end of not having it [the fibroids] reoccur."

Participants expressed subtle differences in their fertility concerns. Two women felt that surgery was the best way to "optimize" (Gabrielle; age 28, M) their chances of pregnancy. It is not clear whether patient-doctor interactions, social networks, or other sources of information informed this concern, but as Chloe (age 31, M) discussed, she felt pressure to move forward with treatment:

...It also put a bit of pressure on moving forward with doing some sort of solution for... [the fibroids] because I would like to have children and I've been informed that there is a chance that [the fibroids] could...prohibit healthy pregnancies or even getting pregnant. So it's put a little bit of sense of urgency, I would say, in having them taken care of.

Two other women noted that they were unsure of how surgical management would impact their ability to get pregnant and wondered if fertility issues would persist after surgery. Lynette detailed her concerns saying, "I don't know how things will change after this... Am I making the right decision having these removed? ... Does [surgery] affect my ability to carry a baby full term?"

Unclear fertility intentions informed the surgical management decisions for three other respondents. Both Cicely (age 38, M) and Regina (age 33, M) wanted to pursue myomectomy in order to "take care of the fibroids," even though neither were sure about their desires for a future pregnancy. Pamela (age 45, H) recounted how her decisions regarding treatment changed over the years. At the time of diagnosis, Pamela, who was recently divorced, wanted to maintain the ability to have children, stating that there may be the "potential to meet someone." Thus, it was important for her to "leave [the option of childbearing] on the table."

Uncertainty about cancer. Underscoring the need for greater patient education about fibroids, a small group of women (n = 3) had concerns that fibroids could be cancerous, which motivated them to pursue surgery. Participants with this concern said that they had often heard stories from family or friends about someone initially being diagnosed with fibroids, later to find out that the person had cancer. As Zoe (age 47, H) detailed, the possibility of fibroids being cancerous is "driving [her] forward to just go ahead and get it [surgery] over with."

The Role Of Community

Fibroid awareness. More than half of the participants (n = 21) in our study reported that they were generally aware of fibroids as a health condition prior to their diagnosis. Women who had at least a college degree (16/21) and/or were privately insured (15/22) were more likely to be aware of fibroids compared with women with less than a college degree (4/16) or not privately insured (7/15). Among the women aware of fibroids, most said that they knew of fibroids from general reproductive health education (n = 5), popular media (n = 1), or the prevalence of fibroids in their own communities (n = 15), indicating that information exchange about fibroids extended beyond the clinical setting for women in our sample.

Although fibroids affect women of all racial/ethnic groups, 14 out of 35 women explicitly mentioned race in response to the general question, "Do you know of other women with fibroids?," suggesting that some respondents may conceptualize fibroids as a condition specific to, or more important for, Black women. Typical was Lynette (age 38, M), who noted: "Most Black women...in [her] life, in [her] age range definitely have experienced or have fibroids, or [were] dealing with them, or have had surgery for them." Reinforcing this observation were five participants who said that they believed that race had a direct influence on the onset of fibroids, citing the "level of melanin" (Lynette) as a primary risk factor. For example, Serena (age 40, H), reframed from engaging in any activities that would reduce her fibroids risk because "[her] risk... [is] being an African-American woman," and "[she] can't change being Black." Of the women with a family history of fibroids (n = 25), eight felt that they were primarily at risk due to both their race and genetics. This was the case for Vanessa (age 48, H), who justified the onset of fibroids as an inevitable condition for Black women with a family history: "There's nothing you can do to prevent it. It's genetic. You're going to get it. It's mostly in Black/African American women anyway." There were some exceptions to this trend, however. Lauren (age 42, M), who acknowledged that many of the Black women in her life had fibroids, also shared how she never believed that she was personally at-risk prior to her diagnosis because she did not experience the "normal" symptoms (e.g., heavy bleeding) like her mother did. Others (n = 9) attributed an increased risk of fibroids to a poor diet. Typical was Zoe (age 47, H), who attributed the high rate of fibroids among Black women to cultural differences in food choices, stating that "Our [Black] culture is different when it comes down to eating. The stuff that we eat can be very rich."

Seeking medical care. The majority of women (n = 28) discussed their fibroids experiences with family, friends, and co-workers. As Whitney (age 42, H) noted, these conversations often occurred among other Black women because fibroids are "such a common thing amongst Black women, that at any given

moment...somehow it comes up." It may also be the case that respondents in our sample felt most comfortable sharing the details of their medical condition with people of a shared community, identity, or interest group (i.e., their "in-group"). Regardless of how conversations arose, social networks played an integral role in helping women make sense of their fibroids and evaluate management options. Social network members shared personal experiences (n = 15), researched relevant information (n = 6), and provided clinician referrals (n = 3). Participants expressed gratefulness for family and friends who accompanied them to consultation visits (n = 2), and provided care throughout the decision making process (n = 17). This support was important for Lauren, who acknowledged that, "when you're going through this, you can forget to ask that question, or you can get lost in what's being told to you." For women who were apprehensive about surgical management (n = 6), family members often encouraged participants to follow-up with clinicians and proceed with surgery. This was the case for Jada (age 32, M) who shared: "My siblings are just telling me it's going to be okay, just take care of it now, don't let it linger on any later than you have, just get the surgery so you can feel good."

Positive support in seeking care for fibroids was not unanimous however. Two women discussed a lack of support from members of their social networks. Although Whitney noted that she shared her experiences with other Black women, she also admitted that her experience with fibroids caused "some othering" in her work environment. Normally an active employee, Whitney described how fibroids made it challenging for her to remain engaged at work; something poorly understood by her colleagues: "People don't necessarily understand how it [fibroids] can impact your life. Because people just see it, 'Oh, yeah, fibroids. You have a heavy period,' and they think that's it." Cultural stereotypes about a Black woman's role in society or sexuality may also influence the level of support within a community. In response, women may feel inclined to reject medical management due to negative perceptions within their communities, particularly from romantic male partners. For example, Cicely (age 38, M), expressed concern about how surgical management may be received by a future partner, stating, "What if I do get married? What am I going to tell my husband about this?" Cicely further discussed how her perceived stigma of reproductive health problems within her community caused her to have "situation depression":

...in the Black or colored [sic] community when they hear about reproductive things, they tend to belittle you. Like "you're half a woman, what's wrong with you?" So that right there is something else that is situationally, can mess with you.

Discussion

We found that the fibroid management decisions of Black women in our sample were shaped by individual interactions with clinicians and social networks, and concerns about fibroid health consequences. Our findings also reflect a broader social context of community norms about gynecologic health, and historical context of inequity for Black women. This study sheds insights on the psychosocial experiences of Black women as they seek fibroid management and can be useful in designing more intersectional, culturally-competent gynecologic care.

Participants detailed important dimensions of the patient-provider dynamic. Women generally desired more information about fibroids, and sometimes perceived this lack of information to signal a clinician's apathy. Consistent with prior studies, ^{22–24} our study participants had concerns about the fertility consequences of fibroids, and some feared that fibroids could be malignant, which underscores the need for improved dialogue between patients and clinicians about fibroids risks since less than one percent of fibroids are malignant. ²⁵ Furthermore, we found that some respondents delayed treatments due to a dismissal of symptoms or false attribution to other conditions by their clinicians. This finding supports prior studies indicating that clinicians are more likely to underestimate and undertreat symptoms for Black women compared with non-Black women, ^{26,27} and provides additional context on why some Black women may delay seeking treatment for symptomatic fibroids. ^{24,28}

Given that fibroids impact more than 80% of all Black women, most participants knew other Black women in their networks with fibroids, and exchanged information about fibroids etiology, risks, and management with them. Broader community norms about the role of race, genetics, and diet on gynecologic health were also featured in conversations, and may have influenced participants' awareness and perceptions about fibroid management. However, fibroid awareness differed by socioeconomic status, suggesting that community dynamics were not the same for all women. Because social networks and larger community norms may influence how women conceptualize fibroids and approach treatment, it is important that clinicians and institutions partner with communities to disseminate culturally-competent information on fibroids care and management.

Previous research demonstrates that women have disparate views about the acceptability of hysterectomy as a fibroid treatment option. ^{21,29} Our study confirms this prior observation but adds some new insights. Not surprisingly, participants who were younger and/or desired fertility were more opposed to hysterectomy. However, some women also expressed medical mistrust in their accounts, questioning whether Black women were valued less in clinical settings compared with non-Black women. These views may be rooted in the historical legacy (e.g., forced sterilizations)³⁰ and contemporary reality (e.g., Black maternal mortality)^{31–33} of inequity against Black women, and may influence how Black women navigate healthcare settings. ^{19,34} These findings provide opportunities for clinicians to address health disparities through an intersectionality lens by understanding how multiple, stigmatized social categories (not limited only to race and gender) intersect with social structures (e.g., racism, sexism, poverty) to produce inequity. ^{10,35} Further research is needed to demonstrate how culturally-competent gynecologic care delivered with a focus on intersectionality may improve patient-provider interactions and health equity.

To our knowledge, this is the first qualitative study to examine within-group comparisons among Black women undergoing surgical treatment for fibroids, which provided a rich opportunity to contextualize Black women's experiences beyond racial comparisons (e.g., Black versus White women). Our study is also the first to ask specifically about patient-doctor interactions among Black women who were undergoing surgical management for fibroids. Participants were diverse with respect to age, education level, and insurance status, which allowed us to assess differences across specific social positions. The

sociodemographic composition of our study population is reflective of the geographical area from which participants were recruited, however, because our respondents were predominately single, highly educated, all insured, and all seeking surgical treatment, we do not know the extent to which our findings generalize to Black women from other backgrounds. Another limitation is we did not explicitly ask women about experiences of discrimination in healthcare settings, which may have elicited more in-depth information.

Conclusion

In this qualitative study of Black women seeking surgical treatment for fibroids, we found that fibroid management decisions were shaped by interactions with clinicians and social networks, fears of malignancy and fertility consequences, and broader social conditions. Given that participants desired more information about fibroids and sometimes felt silenced or devalued in clinical settings, we recommend that clinicians provide more intersectional, culturally-competent care that centers the voices of Black women and acknowledges their specific perspectives, concerns, and social conditions. 10,35-37 Because clinicians help determine when and how women seek fibroid treatment, it is essential that clinicians be trained to address their own implicit biases, partner with communities of color to disseminate information, provide a range of management options, and foster a supportive clinical environment where Black women feel respected and heard when making treatment decisions. 38-40 Collectively, our findings provide new opportunities for clinicians and healthcare institutions to evaluate their approaches to fibroid management, advance patient-centered models of care, and reduce disparities in fibroid management.

Declarations

Ethics approval and consent to participate: All participants provided written informed consent prior to being interviewed. The study was approved by the Institutional Review Board at the George Washington University.

Consent for publication: Not applicable

Availability of data and materials: In order to preserve the anonymity of study participants, the data (e.g., interview transcripts) that support the findings of this study are not publicly available.

Competing interests: Dr. Moawad is a speaker for Intuitive Surgical. All other authors report no conflict of interest.

Funding: This work was supported by the National Institutes of Child Health and Development (R21HD096248), National Center for Advancing Translational Sciences (UL1TR001876, KL2TR001877), The George Washington University Milken School of Public Health, and The George Washington University Office of the Vice President for Research (Cross-disciplinary Research Fund). The content is

solely the responsibility of the authors and does not necessarily represent the official views of any of the funding agencies.

Authors' contributions: BNV contributed to participant recruitment and interviews, performed the qualitative data analyses and interpretation, and led manuscript writing. ARZ conceived and designed the study, interpreted data, and contributed to manuscript writing. LB assisted in study design, qualitative analyses, interpretation of results, and manuscript writing. GM and CM assisted in study design, participant recruitment, and interpretation of results. All authors critically reviewed and approved the final manuscript.

Acknowledgements: We thank Dr. Sabrina McCormick for her assistance with development of the interview guide. We also thank Susanna Mitro, Tyeisha Johnson, Angela Stoehr, Darah Wright, Brenda Trejo, and Ruth Geller who contributed to participant recruitment, conducted qualitative interviews, and ensured data quality.

References

- 1. Baird DD, Dunson DB, Hill MC, Cousins D, Schectman JM. High cumulative incidence of uterine leiomyoma in black and white women: ultrasound evidence. *Am J Obstet Gynecol.* 2003;188(1):100-107.
- 2. Stewart EA, Laughlin-Tommaso SK, Catherino WH, Lalitkumar S, Gupta D, Vollenhoven B. Uterine fibroids. *Nat Rev Dis Primers*. 2016;2.
- 3. Eltoukhi HM, Modi MN, Weston M, Armstrong AY, Stewart EA. The health disparities of uterine fibroid tumors for African American women: a public health issue. *Am J Obstet Gynecol.* 2014;210(3):194-199.
- 4. Borah BJ, Nicholson WK, Bradley L, Stewart EA. The impact of uterine leiomyomas: a national survey of affected women. *Am J Obstet Gynecol.* 2013;209(4):319 e311-319 e320.
- 5. Sengoba KS, Ghant MS, Okeigwe I, Mendoza G, Marsh EE. Racial/Ethnic Differences in Women's Experiences with Symptomatic Uterine Fibroids: a Qualitative Assessment. *J Racial Ethn Health*. 2017;4(2):178-183.
- 6. Borah BJ, Laughlin-Tommaso SK, Myers ER, Yao X, Stewart EA. Association Between Patient Characteristics and Treatment Procedure Among Patients With Uterine Leiomyomas. *Obstet Gynecol.* 2016;127(1):67-77.
- 7. Yao X, Stewart EA, Laughlin-Tommaso SK, Heien HC, Borah BJ. Medical therapies for heavy menstrual bleeding in women with uterine fibroids: a retrospective analysis of a large commercially insured population in the USA. *Bjog-Int J Obstet Gy.* 2017;124(2):322-330.
- 8. Metzl JM, Hansen H. Structural competency: Theorizing a new medical engagement with stigma and inequality. *Social Science & Medicine*. 2014;103:126-133.

- 9. Bauer GR. Incorporating intersectionality theory into population health research methodology: Challenges and the potential to advance health equity. *Social Science & Medicine*. 2014;110:10-17.
- 10. Bowleg L. The problem with the phrase women and minorities: intersectionality-an important theoretical framework for public health. *Am J Public Health*. 2012;102(7):1267-1273.
- 11. Trotter RT. Qualitative research sample design and sample size: Resolving and unresolved issues and inferential imperatives. *Prev Med.* 2012;55(5):398-400.
- 12. Morse JM. Determining sample size. *Qual Health Res.* 2000;10(1):3-5.
- 13. Zota AR, Geller RJ, Calafat AM, Marfori CQ, Baccarelli AA, Moawad GN. Phthalates exposure and uterine fibroid burden among women undergoing surgical treatment for fibroids: a preliminary study. *Fertil Steril.* 2019;111(1):112-121.
- 14. Patton MQ. Qualitative Research and Evaluation Methods. Third ed. Thousand Oaks, CA: Sage; 2002.
- 15. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology.* 2006;3(2):77-101.
- 16. Lincoln YS, Guba, E.G. . Naturalistic Inquiry. Beverly Hills, CA: Sage; 1985.
- 17. Geertz C. From the natives' point of view. American Scientist. 1975;63:47-53.
- 18. Geertz C. The Interpretation of Cultures. New York: Basic Books; 1973.
- 19. Rosenthal L, Lobel M. Stereotypes of Black American Women Related to Sexuality and Motherhood. *Psychol Women Q.* 2016;40(3):414-427.
- 20. Wyatt GE. *Stolen Women: Reclaiming our sexuality, taking back our lives.* New York: John Wiley & Sons; 1997.
- 21. Augustus CE. Beliefs and perceptions of African American women who have had hysterectomy. *J Transcult Nurs.* 2002;13(4):296-302.
- 22. Wu SM, Chao Yu YM, Yang CF, Che HL. Decision-making tree for women considering hysterectomy. *J Adv Nurs.* 2005;51(4):361-368.
- 23. Brito LGO, Panobianco MS, Sabino-de-Freitas MM, et al. Uterine leiomyoma: understanding the impact of symptoms on womens' lives. *Reprod Health.* 2014;11.
- 24. Stewart EA, Nicholson WK, Bradley L, Borah BJ. The Burden of Uterine Fibroids for African-American Women: Results of a National Survey. *J Womens Health*. 2013;22(10):807-816.
- 25. Parker WH, Fu YS, Berek JS. Uterine Sarcoma in Patients Operated on for Presumed Leiomyoma and Rapidly Growing Leiomyoma. *Obstet Gynecol.* 1994;83(3):414-418.
- 26. Nelson A. Unequal treatment: Confronting racial and ethnic disparities in health care. *J Natl Med Assoc.* 2002;94(8):666-668.
- 27. Hoffman KM, Trawalter S, Axt JR, Oliver MN. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proc Natl Acad Sci U S A.* 2016;113(16):4296-4301.
- 28. Ghant MS, Sengoba KS, Vogelzang R, Lawson AK, Marsh EE. An Altered Perception of Normal: Understanding Causes for Treatment Delay in Women with Symptomatic Uterine Fibroids. *J Womens*

- Health (Larchmt). 2016;25(8):846-852.
- 29. Askew J. A qualitative comparison of women's attitudes toward hysterectomy and myomectomy. *Health Care Women Int.* 2009;30(8):728-742.
- 30. Beal FM. Double Jeopardy: To Be Black and Female. Vol 8: Project Muse; 2008.
- 31. McLemore MR, Altman MR, Cooper N, Williams S, Rand L, Franck L. Health care experiences of pregnant, birthing and postnatal women of color at risk for preterm birth. *Social Science & Medicine*. 2018;201:127-135.
- 32. Earnshaw VA, Rosenthal L, Lewis JB, et al. Maternal Experiences with Everyday Discrimination and Infant Birth Weight: A Test of Mediators and Moderators Among Young, Urban Women of Color. *Ann Behav Med.* 2013;45(1):13-23.
- 33. Giscombe CL, Lobel M. Explaining disproportionately high rates of adverse birth outcomes among African Americans: The impact of stress, racism, and related factors in pregnancy. *Psychol Bull.* 2005;131(5):662-683.
- 34. Cuevas AG, O'Brien K, Saha S. African American Experiences in Healthcare: "I Always Feel Like I'm Getting Skipped Over". *Health Psychol.* 2016;35(9):987-995.
- 35. Crenshaw K. Mapping the Margins Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review Vol 43, No 6, July 1991.* 1993:1241-1299.
- 36. Betancourt JR, Green AR, Carrillo JE, Ananeh-Firempong O. Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Rep.* 2003;118(4):293-302.
- 37. Napier AD, Ancarno C, Butler B, et al. Culture and health. *Lancet.* 2014;384(9954):1607-1639.
- 38. Hall WJ, Chapman MV, Lee KM, et al. Implicit Racial/Ethnic Bias Among Health Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review. *Am J Public Health*. 2015;105(12):E60-E76.
- 39. Kreps GL. Communication and racial inequities in health care. Am Behav Sci. 2006;49(6):760-774.
- 40. Altman MR, Oseguera T, McLemore MR, Kantrowitz-Gordon I, Franck LS, Lyndon A. Information and power: Women of color's experiences interacting with health care providers in pregnancy and birth. *Social science & medicine.* 2019;238:112491.