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

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### Abstract

**Background:** Black women are more likely to undergo surgery for uterine fibroids compared with non-Black women. However, few studies have characterized the psychosocial experiences of Black women seeking fibroid treatment. We 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 across age and socioeconomic status (SES).

**Methods:** We conducted semi-structured interviews with 37 Black women undergoing surgery for fibroid management. We used a thematic analysis to code transcripts and identify themes.

**Results:** Participants were predominately single, college educated, and insured. Respondents reported that patient-doctor interactions, support from social networks, fertility consequences, and fear of fibroid malignancy influenced their fibroid management decisions. Knowledge and perceptions of fibroids were also influenced by 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.

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**Conclusions:** Fibroid management decisions were influenced not only by 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 intersectional gynecologic care that centers the voices of Black women seeking fibroid treatment.

### Keywords

Uterine fibroids; qualitative research; health disparities; Black women

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### Introduction

Uterine leiomyomas (fibroids) are non-cancerous tumors in the uterus that develop in the majority of reproductive-aged women in the United States (Baird et al., 2003; Stewart et al., 2016). Black women are disproportionately impacted by fibroids, often experiencing more severe morbidity (Baird et al., 2003; Eltoukhi et al., 2014). Despite advancements in alternative management options, myomectomy (surgical removal of fibroid tissue) and hysterectomy (surgical removal of the uterus) remain mainstay treatment options for patients with symptomatic fibroids (Stewart et al., 2016). Although hysterectomy is the least preferred fibroid treatment by women regardless of fertility intentions (Borah et al., 2013), and Black women are generally more opposed to surgical management compared with non-Black women (Sengoba et al., 2017), Black women are still more likely to undergo surgery for fibroids (Eltoukhi et al., 2014).

Clinicians may recommend fibroid treatments based on the size, type, and location of fibroids, as well as the severity of symptoms or patient fertility intentions (Stewart et al., 2016). Little is known, however, 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 (Borah et al., 2016; Yao et al., 2017); 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 medical choices. These factors are important given the growing body of research on intersectionality and structural competency that suggests experiences in healthcare settings extend beyond individual-level interactions and are also shaped by intersecting social conditions (Metzl & Hansen, 2014; Bauer, 2014; Bowleg, 2012).

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 does discrimination by race, sex, and class manifest in their treatment-seeking experiences, and (c) do their experiences vary by age and socioeconomic status.

## Materials and Methods

### Participants.

We recruited women into an epidemiologic study on uterine fibroids from 2014-2017 at an urban academic 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, 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 (Trotter, 2012). Estimating sample size in qualitative studies depends on various factors, including the study design and quality of the data, and studies can include as few as 6-10 participants (Morse, 2000). 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 (Morse, 2000). Our sample consists of 37 self-identified Black/African American women who completed the qualitative interview. The mean age of our sample was 38.8 years (range 26-53), and participants were predominately single, nulliparous, privately insured, college educated, and undergoing hysterectomy (Table 1). Information about fibroid burden (e.g., number of fibroids, uterine volume) is published elsewhere (Zota et al., 2019; 2020).

### Procedures.

Trained female research assistants (3 Black, 1 Latina, 1 White) conducted semi-structured interviews with participants either over the phone or in a private space at the medical center. Most interviews were conducted prior to surgery (n=30); however, some (n=7) were conducted up to three weeks after surgery to accommodate participant schedules. We utilized a semi-structured interview guide to elicit conversation about pertinent topics while allowing flexibility for patients to share their experiences, and to ensure that data obtained for each participant were systematic (Patton, 2002). The open-ended interview guide included questions about women’s experiences with receiving a fibroids diagnosis, their perceptions about fibroid risks, their interactions with clinicians for fibroids care, and the influence of their social networks on fibroid management decisions. The complete interview guide is included as supplemental material. The average length of each interview was 11.28 minutes (range 2.53-25.49). We also obtained information on educational attainment through a standardized questionnaire, and reviewed participant medical records to confirm age, menopausal status, and insurance coverage. 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 by the research team, with original recordings preserved for reference. We conducted a thematic analysis to develop codes and identify themes (Braun & Clarke, 2006). Thematic analysis is a strategy used to identify, analyze, interpret, and report patterns in qualitative data (Braun & Clarke, 2006). The first author thoroughly read the primary transcripts at least twice to become familiar with the data. Guided by the research questions, the first author developed a preliminary codebook

with initial codes (e.g., patient-doctor communication, race) and documented theoretical and reflective thoughts for each transcript. The study authors (BV, LB, and AZ) met regularly to discuss the preliminary codebook and compare coding to the transcripts. Using NVivo 10 (QSR International), 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 (BV, LB, AZ) reviewed and refined coded transcripts, and the first author 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 vs. 40 years of age), educational attainment (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. The attribute data was exported and differences in participant accounts were manually evaluated using Microsoft Excel. BV, LB, and AZ collaboratively interpreted coding into themes. Themes identified during the coding process and after coding was complete were reviewed by all the study authors for relevance to the research questions until consensus was reached. We consistently referenced the transcripts and research questions to resolve discrepancies in interpretation of themes, and to ensure that participant accounts supported the conclusions drawn.

### **Trustworthiness of analyses.**

We used four criteria to assess the quality of our analyses: prolonged engagement with the data, credibility, transferability, and confirmability (Lincoln & Guba, 1985). 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 (Geertz, 1973; 1975). 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. The authors (2 Black women, 1 White woman, 1 White man, 1 Indian American woman) also used reflexive approaches (e.g., memo writing, critical self-evaluation) throughout the study, acknowledging that our values, beliefs, knowledge, and biases may affect the research process and outcome (Berger, 2015). We aimed to emphasize the ways in which Black women constructed their own experiences seeking fibroid treatment and to center their stories in the present analysis.

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 women.

## Results

Participants detailed their experiences seeking treatment for fibroids. Guided by the research questions, we have organized the findings around four key themes identified in the analysis: 1) patient-provider interactions, 2) the social and historical value of the uterus, 3) fertility consequences and fear of malignancy, and 4) the role of community (Table 2).

### Patient-provider interactions

**Diagnosis experience.**—Participants (N=37) discussed their fibroids diagnosis experiences, with women discovering fibroids through routine gynecologic visits (n=28), emergency room encounters (n=6), or incidentally during pregnancy (n=3). For some, poor patient-provider interactions were a barrier to receiving a fibroids diagnosis (n=6). Women described how their clinicians initially dismissed symptoms (n=3), or wrongly attributed symptoms to other issues (n=3). Typical was Kierra (age 37, H), who recalled that her clinician silenced her concerns by saying, “Oh, you’re fine,” in response to complaints about heavy bleeding. Lauren (age 42, M) shared how her clinician attributed her fibroid-related symptoms to weight gain and advised a wellness program. Lacking a definitive diagnosis and management plan that could alleviate her symptoms, Nina (age 38, H) recalled 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 perceived risk of fibroid complications 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 20s. She recounted, “The doctor explained that most women had fibroids ... 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. Typical was Pamela (age 45, H) who shared:

... 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 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 opinions from new clinicians. For example, Halle (age 36, M), unsatisfied with information from her first clinician, "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 and social networks to help make informed decisions about treatment.

### **The social and historical value of the uterus**

Women shared diverse perspectives regarding fibroid management options. Thirteen women reported that their clinicians initially recommended medication to manage symptoms. Four out of the 13 women may have perceived medication as a temporary fix, stating that they were not interested in taking pain medication or hormonal contraception. 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 women expressed neutral or positive feelings about undergoing hysterectomy, while the other four 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 (age 42, M), on the other hand, was skeptical of her clinician's recommendation for hysterectomy, and questioned whether the recommendation was for 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? ... 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 intersectional discrimination and devaluation that is explicitly or implicitly expressed in contemporary healthcare settings, and that fosters medical mistrust or skepticism (Prather et al., 2018). Lauren, who spoke candidly with her family and friends about fibroids, echoed the impact of this historical legacy in her account, questioning 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 concerns that influenced their surgical decisions. 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, “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.” Cathy (age 53, H), however, 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.” The exception to this trend was Alexa (age 37, H) who 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 which sources 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 (age 38, M) detailed her concerns saying, “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 medical 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,” although neither were sure about their desires for a future pregnancy. Pamela (age 45, H) recounted how her treatment decisions changed over the years. At the time of diagnosis, Pamela 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.**—A small group of women (n=3) were motivated to pursue surgery due to concerns that fibroids could be cancerous. These participants 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.**—Most women (n=21) reported that they were 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 those who were aware of fibroids, most said that they knew of fibroids from general 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 these women.

Although fibroids affect women from 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 that most Black women in her life had dealt with fibroids. 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), refrained 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. For example, Vanessa (age 48, H) described 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 expected to have fibroids because she did not experience 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.**—Most 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.



Regardless of how conversations arose, social networks were integral in helping women make sense of their fibroids and evaluate medical options. Social network members shared personal experiences (n=15), researched relevant information (n=6), and provided clinician referrals (n=3). Participants expressed gratitude 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 (age 42, M), 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 surgery (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 ... 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.”

Participants were not unanimous in describing positive support when they sought care for fibroids, however. Although Whitney (age 42, H) noted that she shared her experiences with other Black women, she also admitted that her colleagues at work poorly understood her experience with fibroids, because “people don’t necessarily understand how it [fibroids] can impact your life.” Cultural stereotypes about a Black woman’s role in society or sexuality may also influence the level of support within a community (Rosenthal & Lobel, 2016; Augustus, 2002). In response, women may feel inclined to reject medical intervention due to negative perceptions within their communities (Augustus, 2002). For example, Cicely (age 38, M) 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 a historical context of inequity for Black women. This study provides insights on the psychosocial experiences of Black women as they seek fibroid management and can be useful in designing more intersectional, structurally 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. As in prior studies (Wu et al., 2005; Brito et al., 2014; Stewart et al. 2013), our study participants had concerns about the fertility consequences of fibroids, and some feared that fibroids could be malignant— even though less than one percent of fibroids are malignant (Parker et al., 1994). This underscores the need for improved dialogue between patients and clinicians about fibroids risks. Furthermore, we found that some respondents delayed treatment due to a dismissal of

symptoms or incorrect 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 (Nelson, 2002; Hoffman et al., 2016), and provides additional context on why some Black women may delay seeking treatment for symptomatic fibroids (Stewart et al., 2013; Ghant et al., 2016).

Given that fibroids impact more than 80% of all Black women (Baird et al., 2003), it is not surprising that most participants knew other Black women in their networks with fibroids, and exchanged information about fibroids with them. Interestingly, women who had a least a college degree and/or were privately insured were more aware of fibroids as a health condition compared with women of lower socioeconomic status, suggesting that community dynamics were not the same for all women. Because social networks and community norms may influence how women conceptualize fibroids and approach treatment, it is important that clinicians and institutions partner with communities to disseminate culturally relevant information on fibroids care and management.

Previous research demonstrates that women have disparate views about the acceptability of hysterectomy as a fibroid treatment option (Augustus, 2002; Askew, 2009). 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) and contemporary reality (e.g., Black maternal mortality) of inequity against Black women, and may influence how Black women navigate healthcare settings (Prather et al., 2018; McLemore et al., 2018; Earnshaw et al., 2013; Cuevas et al., 2016). These findings underscore the need for clinicians to approach healthcare with an intersectionality lens by understanding how multiple stigmatized social categories (not limited only to race and gender) intersect with structural discrimination (e.g., racism, sexism, poverty) to produce inequity (Bowleg, 2012; Crenshaw, 1991). Further research is needed to demonstrate how intersectional gynecologic care 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 surgery for fibroids. Our approach 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-provider interactions among Black women seeking surgical management for fibroids. Participants' diversity with respect to age, education level, and insurance type allowed us to assess differences across specific social positions. The sociodemographic composition of our sample is reflective of the Washington, D.C. metropolitan area; however, because respondents were predominately single, highly educated, all insured, and all seeking surgical treatment, we do not know whether our findings generalize to Black women from other backgrounds. Another limitation is the brevity of some participant interviews (range 2.53-25.49 min); shorter conversations may have obscured further themes. Moreover, we did not explicitly ask questions about experiences of discrimination in healthcare settings, which may have elicited more in-depth information.

## Implications for Practice

Given that participants desired more information about fibroids and sometimes felt devalued in clinical settings, we recommend that clinicians be trained to address their own biases, and provide more intersectional, structurally competent care that centers the voices of Black women and acknowledges their specific perspectives and social conditions (Bowleg, 2012; Crenshaw, 1991; Metzl & Hansen, 2014; Napier, 2014; Hall et al., 2015). Because clinicians help determine when and how women seek fibroid treatment (Kreps, 2006; Altman et al., 2019), it is essential that clinicians partner with communities of color to disseminate information, foster a supportive clinical environment for Black women that takes the psychosocial burden and decision making processes related to fibroids seriously, and provide a range of fibroid management options. Collectively, our findings provide new opportunities for clinicians and healthcare institutions to evaluate their approaches to fibroids care and reduce disparities in fibroids management.

## Conclusions

In this qualitative study of Black women seeking surgical treatment for fibroids, we found that management decisions were shaped by interactions with clinicians and social networks, fears of malignancy and fertility consequences, and broader socio-historical conditions.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## Biographies

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### Data Statement:

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.

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**Table 1.**

Demographic Characteristics of Black Interview Participants (N=37)

Characteristic	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)
9 <sup>th</sup> grade or less	1 (2.7)
Surgical procedure *	
Hysterectomy	20 (55.6)
Myomectomy	16 (44.4)

\* One participant did not follow through with surgery but expressed an intention to have a myomectomy at the time of the interview.

**Table 2.** Themes, major findings, and supportive quotes from the qualitative analysis of Black women’s experiences seeking fibroid treatment

Themes	Main Findings	Supportive Quotes
<p><b>Patient-Provider Interactions</b></p>	<p><i>Diagnosis experience:</i> Fibroids diagnosis experiences impacted how participants navigated fibroid care and management.</p>	<p>“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.” (Nina, age 38, H)</p> <p>“The doctor explained that most women had fibroids ... and that mine were so small that it was nothing to even be alarmed about.” (Ashanti, age 51, H)</p>
<p><b>The Social and Historical Value of the Uterus</b></p>	<p><i>Patient expectations for clinicians:</i> Women expressed the desire for more information from clinicians about fibroids, as well as a range of treatment options.</p> <p>While some respondents expressed positive or neutral feelings about hysterectomy as a treatment option, others reacted negatively to the recommendation, conveying medical mistrust.</p>	<p>“[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.” (Pamela, age 45, H)</p> <p>“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?” (Lauren, age 42, M)</p>
<p><b>Fertility Consequences and Fear of Malignancy</b></p>	<p><i>Fertility consequences:</i> Women under 40 years old were generally concerned about the fertility consequences of fibroids, with differing perspectives on whether surgical management would be helpful or harmful for pregnancy.</p> <p><i>Uncertainty about cancer:</i> Some women were motivated to pursue surgery due to concerns that fibroids could be cancerous.</p>	<p>“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.” (Chloe, age 31, M)</p> <p>“Am I making the right decision having these removed? ... Does [surgery] affect my ability to carry a baby full term?” (Lynette, age 38, M)</p> <p>“... [cancer] is what’s really, is driving me forward to just go ahead and get it over with.” (Zoe, age 47, H)</p>
<p><b>The Role of Community</b></p>	<p><i>Fibroid awareness:</i> Most respondents were aware of fibroids as a health condition prior to their diagnosis and were often informed by other Black women.</p> <p><i>Seeking medical care:</i> Social networks and community norms about reproductive health were instrumental in how Black participants conceptualized fibroids and evaluated their medical options.</p>	<p>“Most Black women, probably, in my life, in my age range definitely have experienced or have fibroids, or dealing with them, or have had surgery for them.” (Lynette, age 38, M)</p> <p>“My siblings are just telling me... 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.” (Jada, age 32, M)</p> <p>“... 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?’” (Cicely, age 38, M)</p>