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Patient Recommendations for Shared Decision-Making in Uterine Fibroid Treatment Decisions

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Abstract

Uterine fibroids are noncancerous tumors associated with significant morbidity among symptomatic patients. While medical and surgical treatments have expanded, hysterectomy remains common. We interviewed women diagnosed with uterine fibroids ($n = 47$) to explore their experiences and recommendations for shared decision-making. A majority were non-Hispanic Black, highly educated (51.1%), and had graduate degrees (40.4%). Participants with both positive and negative provider experiences expressed a desire for a more proactive therapeutic approach, including a presentation by their provider of the spectrum of medical and surgical treatment options, and greater provider recognition of the impact of symptoms on quality of life. Women advocated for expanded shared decision-making that acknowledged their contribution to their own treatment plan and felt early screening and improved patient/provider education of uterine fibroid symptoms would facilitate greater congruence between treatment approaches and patient goals. Perceptions of insufficient input into their treatment plans frequently served as a barrier to care-seeking and treatment acceptance among women with uterine fibroid symptoms. Improved discussion of treatment options in the context of the unique symptom burden and values of the patient may facilitate greater provider trust and acceptance of uterine fibroid treatment.

Keywords

uterine fibroids, diagnosis, quality of life, patient dismissal, uterine leiomyoma, shared decision-making

Introduction

Uterine fibroids are noncancerous tumors of the uterus that are present in 70% of self-reported White women and more than 80% of self-reported Black women during their lifetime (1). Many women are asymptomatic, however, 25% to 50% experience symptoms (2), including heavy and prolonged menstrual bleeding, pelvic pain, bladder and bowel dysfunction, and abdominal protrusion (3–5). Non-Hispanic Black (NHB) women have a higher prevalence of uterine fibroids and increased disease burden (6,7). Approximately 5% to 10% of cases of female infertility are associated with uterine fibroids (8).

Uterine fibroids are manageable with medical and surgical interventions for symptom relief and fertility preservation (9–11). The first line of treatment for heavy menstrual bleeding associated with uterine fibroids is medical therapy; just under 80% of uterine fibroid patients are prescribed short-acting reversible contraceptive steroids (12). However, despite the increasing array of treatments, including minimally invasive and uterine-sparing surgical approaches, hysterectomy accounts for 75% of all fibroid-related procedures in the US (13–16,17).

While the prevalence of uterine fibroid-related hysterectomy and uterine-sparing procedures are known (18), less attention is given to the shared decision-making process during which patients and providers weigh treatment

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decisions. We conducted a community-engaged qualitative study examining women's experiences and perceptions of the diagnosis and management of uterine fibroids, including the potential impact of provider interactions on decision-making, and patient recommendations for improvements to the shared decision-making process.

Methods

Recruitment

In accordance with principles of community-engaged research (19), this study was conducted in collaboration with The Fibroid Foundation, a nonprofit organization offering education and support to women diagnosed with uterine fibroids. We used social media recruitment to recruit a sample of women with experience of uterine fibroids with diverse demographics and experiences seeking gynecology care. A link to an online screening survey was disseminated on The Fibroid Foundation's social media platforms. Participants who met inclusion criteria were invited to participate in a telephone interview. Criteria for inclusion included a self-reported diagnosis of uterine fibroids, reproductive age (18-45 years old), ability to speak English, and US-based care. Participants were enrolled following a return of their written informed consent and Health Insurance Portability and Accountability Act (HIPAA) authorization. After interview completion, participants were sent a gift basket curated by The Fibroid Foundation as thanks for their participation. The study was approved by the Institutional Review Board of Mayo Clinic.

Data Collection

Two researchers with expertise in qualitative methods (KR and MA) conducted semi-structured interviews between August 2018 and January 2019 using an interview guide (Appendix in the Supplemental Material) developed by the community and patient-engaged research team with expertise in uterine fibroids, assisted reproductive technologies, patient experience, epidemiology, and bioethics. The interview guide consisted of open-ended questions regarding uterine fibroid diagnosis, treatment, experiences with providers, reproduction, and perception of care. Probing follow-up questions were asked at the discretion of the interviewer. This approach was chosen to elicit unanticipated themes discussed by participants in accordance with the principles of grounded theory (20). Interviews were completed until thematic saturation (ie, no new topics or themes emerged in the interview) was achieved (21). The average interview length was 49 min. Interviews were audio-recorded, deidentified, and transcribed verbatim.

Table 1. Participant Demographics.

	N (%)
Mean age (range)	37.2 (27-45)
Ethnicity	
Non-Hispanic White	19 (40.4)
Non-Hispanic Black	24 (51.1)
Hispanic	2 (4.3)
Other ethnicity	2 (4.2)
Education (*n* = 47)	
High school	1 (2.1)
Some college	7 (14.9)
2-year college degree	2 (4.3)
4-year college degree	18 (38.3)
Graduate/professional education	19 (40.4)
Age at diagnosis (*n* = 46)	
<18 years	1 (2.2)
20-24 years	8 (17.4)
25-29 years	12 (26.1)
30-34 years	14 (30.4)
35-39 years	5 (10.9)
40-45 years	6 (13.0)

Data Analysis

The research team developed a codebook from analysis of $n = 5$ (10.4%) transcripts based on iterative themes that were inductively identified (20). NVivo 12 was used for qualitative analysis. Two researchers (KR and AG) coded $n = 12$ (25%) of transcripts to consensus with additional refinement and finalization of the codebook. The remainder of the transcripts was coded by one researcher (AG) with trends and coded material discussed weekly with the second coder (KR) to maintain research rigor. We report here on uterine fibroid diagnosis, experiences with providers, patient evaluation of surgical treatment options, and care and treatment recommendations (see Appendix Table A in the Supplemental Material for sample coding schema). Representative quotations are presented according to the published guidelines on reporting qualitative research (22). Quotations were minimally edited for readability.

Results

Demographics

The screening survey was completed by 107 individuals who met inclusion criteria. Fifty-seven of these women returned their HIPAA authorization and/or scheduled an interview with 47 participants completing an interview (43.9% response rate). Table 1 presents participant demographics.

Experiences with Uterine Fibroid Diagnosis

The majority of participants reported being unaware of uterine fibroids before their diagnosis. With the exception of 1 non-Hispanic white (NHW) participant, all women with prior knowledge ($n = 12$) were NHB.

> It was more the physician brought it up to me, as that might not be normal. I just assumed it was, because I knew people in my family had heavier periods (NHB, 33-year-old).

In retrospect, many symptomatic participants realized they had been experiencing uterine fibroid symptoms for many years before seeking medical treatment (Table 2). These participants frequently believed heavy bleeding was normal due to family history and lack of awareness that nonmenstrual symptoms (eg, frequent urination and abdominal pain/fullness) may be caused by uterine fibroids. Participants who were asymptomatic at diagnosis were undergoing an annual gynecology exam ($n = 8$) or infertility evaluation ($n = 1$) when the uterine fibroid was detected. Eight asymptomatic patients later developed symptoms; the other asymptomatic patient was scheduled for a hysterectomy due to uterine size. Several participants expressed a wish that they had pursued a diagnosis before the onset of acute symptoms, subfertility, and/or the need for surgical treatment.

> I was confused [at the diagnosis]. I didn't know what fibroids were…I was just confused about why me…Then I kicked myself, like oh, I should have come sooner to try to figure out what was going on because I just allowed myself to live with it for so long (NHB, 32-year-old).

Participants described a range of perceptions of the clinical encounter, including some who experienced positive interactions where they felt their provider addressed their fibroid symptoms appropriately in response to their clinical presentation and reviewed treatment options in light of their therapeutic goals.

> I felt comfortable knowing that my results were reviewed and the time that my doctor took with me to really explain things more than just what it said according to the radiologist, knowing my history, knowing some of the next steps and knowing that I wanna begin—I want have a child sooner rather than later (NHW, 28-year-old).

However, several participants said they described their symptoms to their provider multiple times over the course of several visits before they were evaluated and diagnosed. In a few cases, this delay lasted several years. Some participants felt their symptoms were dismissed by their provider as normal menstruation, especially if the primary symptom was acute pain associated with menstrual bleeding. A few participants described presenting to the emergency room with acute pain and being told that uterine fibroids do not cause pain.

Table 2. Time From Recognition of Symptom Onset to Diagnosis.

Length of time from symptom onset to diagnosis	*n* (%)
Asymptomatic	9 (19.1)
<1 year	6 (12.8)
1-2 years	8 (17.0)
2-3 years	4 (8.5)
3-4 years	1 (2.1)
5+ years	4 (8.5)
Since menstruation onset ("always had symptoms")	5 (10.6)
Not sure	5 (10.6)
Secondary diagnosis	5 (10.6)

> I've had trips to the ER for pain or this or that, and when doctors look at you and say 'oh, no, uterine fibroids are nothing'—they can't cause pain or you're just overacting, I think the lack of understanding by some doctors not comprehending what they can really do to a woman is just a slap in the face (NHW, 38-year-old).

Some women reported the perception that providers used or recommended courses of oral contraceptives without a full diagnostic work-up as a "quick-fix" or default therapy for unexplained menstrual symptoms. This was often interpreted by the women as a failure of the provider to take their symptoms seriously and sometimes led to a distrust of their provider and feelings of alienation.

> Throughout this whole process, nobody ever mentioned that there could be an underlying problem. Nobody ever mentioned the word fibroid or said, 'Maybe you're having all these problems. Let's do an ultrasound.' None of that ever happened. They were just like, 'Okay. You need birth control.'…There were multiple times that I think I can pinpoint where things were missed, that I wasn't educated, and it didn't necessarily need to get to this point (NHW, 30-year-old).

Several participants perceived male providers as being less empathetic and understanding of the severity of symptoms and their impact on quality of life. Women with symptom onset in their teenage years or early 20s, in particular, were more likely to report feeling dismissed and reported difficulty convincing providers that they were not overreacting to normal menstrual symptoms.

> For three years and I had been sharing my concerns with my OB/GYN at the annual appointment every year, because I was so young and I'm white my doctors would be like no, heavy bleeding is normal. Go take some ibuprofen and kind of just blew me off (NHW, 31-year-old).

In response to these perceptions, several participants reported delaying future care or cycling through several providers before they found one they felt was responsive. Some participants specifically sought out providers of the same gender and/or race or a fibroid specialist to receive the care they felt was more empathetic, proactive, and/or specialized.

> I think that certainly older male doctors are very set in their understandings of the way that they're supposed to treat patients and the way that they can dismiss pain in certain people…I also think that the fact that they're women means that they're less—hopefully at least—they are less likely to be dismissive of a woman saying, "No, I'm actually

> in pain, and this is actually impairing my life. I need a solution, not to be placated" (NHW, 37-year-old).

Provider Discussion of Surgical Treatment Options

Participants often reported dismay when providers suggested surgery, especially hysterectomy, as the first line or only treatment option and felt they were being limited to a narrow set of therapies incongruent with their treatment and fertility goals. This led to a perception that providers considered them passive actors in the decision-making process. Participants expressed a desire for more exploration of nonsurgical approaches before discussing surgical options.

> I've yet to run into a doctor that I felt like they cared enough to know what's causing this, or tried to help me, besides having the doctor do the myomectomy… I feel like because of my case being so severe, that they're just used to treating the one and two, or three or four, and it's just—what's the word —like a fast food restaurant. You have option one, two, three and four, and you don't fit into those boxes, then there's nothing we could do (Hispanic, 36-year-old).

Several women stated they refused further care from a provider if the provider was unwilling to consider nonsurgical and/or alternative therapies. Some participants also specifically sought out a minimally invasive surgeon after being told that their provider only offered, or would only consider, an open surgical approach. A few women recounted that feeling dismissed by providers led them to seek alternative medical advice through social media or other online sources.

> [When provider said] "Hysterectomy," I decided that I was not gonna go back to her, 'cause there were no other options…I know things now, you can do all these diet changes, going vegetarian or vegan or whatever, based on these other research and studies that I've studied. According to her, none of those things ever work. Because you immediately just want to cut, I have issue with that (NHB, 40-year-old).

Over half ($n = 28$) of participants had completed a surgical procedure (Table 3). The decline in quality of life was frequently cited as the primary reason women eventually pursued or accepted surgical intervention. But most participants could not recall having a discussion with their provider about quality of life concerns.

> I'm in such pain. I can't walk. I have to work from home for work. I picked up a second job and I can't work that second job during that week because I can't stand for periods of time and I need to be close to a bathroom. For better quality of life, I decided to pursue surgery (NHB, 34-year-old).

Table 3. Medical and Surgical Treatments Described by Participants.

Treatment option ($n = 47$)	n
Any medication[a]	26
NSAIDS	8
Iron supplements	7
Oral contraceptives	14
IUD	2
GnRH agonist	4
Other	6
Any surgery[b]	28
Myomectomy[c]	24
Laparoscopic or robotic	8
Abdominal	11
Hysteroscopic	5
Not specified	3
Minimally invasive	4
MRI-guided ultrasound	1
Uterine artery embolization	1
Myolysis	1
D&C	1
Hysterectomy[c]	2
No treatment (medical or surgical)	4

Abbreviations: NSAIDS, nonsteroidal anti-inflammatory drugs; IUD, intrauterine device; GnRH, gonadotropin-releasing hormone; MRI, magnetic resonance imaging; D&C, dilation and curettage.

[a] $n = 17$ attempted medical management before undergoing a surgical procedure (including those with scheduled procedures).

[b] Includes $n = 7$ participants who completed more than one type of surgical procedure.

[c] Additional participants had myomectomies ($n = 4$) and hysterectomies scheduled ($n = 5$) at the time of the interview.

Participant Suggestions for Improved Clinical Encounter

Almost all participants expressed a wish that providers had greater knowledge of women's reproductive health and understanding of uterine fibroid symptoms. Even if they were generally satisfied with their care, some women felt the range of currently available treatment options, including minimally invasive approaches, needed greater awareness among gynecology providers and patients.

> I just wish there was more information about fibroids out there. From my understanding or from my viewpoint, at least, it seems like there seems to be a little bit of misinformation because of how adamant my doctors were about, no, fibroids don't cause pain (NHW, 33-year-old).

Many participants suggested that educating patients on uterine fibroids and how to identify potential symptoms should begin in the teens and early 20s. Several women suggested that routine ultrasound screening for uterine fibroids as the standard of care would allow women to make early reproductive and therapeutic choices. Almost all participants desired a greater understanding of symptom impact on quality of life.

> I've been told a couple different times that this is just—it's not life threatening, so it's not that major. Work through it. That's not helping you when you have a ten-hour workday and you're exhausted. I definitely would love to see more empathy…I haven't experienced any of that, to be honest with you, from the medical professionals that I've seen, thus far (NHB, 44-year-old).

While women understood that myomectomy and, under certain circumstances, hysterectomy are recommended for uterine fibroids, many participants asked for a much broader discussion of their treatment options that explained why surgery was the only viable option. Participants reported a desire to be active shared decision makers and engage in in-depth discussion and consideration of their reproductive options and goals in treatment decisions.

Discussion

Many participants indicated that their own lack of knowledge of uterine fibroid signs contributed to a delayed diagnosis, similar to other reports (23,24). However, even after reporting symptoms, a subset of participants reported feeling as if their provider ignored or dismissed their concerns (25). National survey findings indicate women wait an average of 3.6 years to seek treatment for uterine fibroids and ~41% consult at least 2 health care providers before they are diagnosed (26,27). In some participant accounts, diagnostic delay appeared to be attributable to a lack of knowledge about the scope of uterine fibroid symptoms. While the more serious reports of provider avoidance were among nongynecology specialists, some women felt that even gynecology providers tended to downplay patient experience on the basis of patient age and ethnicity. This trend may also be reflective of unconscious gender and racial pain bias reported in the literature (28–31); women perceived their age, race, ethnicity, and provider gender as factors in the dismissal of their menstrual symptoms and pelvic/abdominal pain. NHB patients have also historically been perceived as having higher pain tolerance (32) further contributing to the intersectional experience of NHB women seeking gynecological care.

Participants felt that their personal goals for treatment were undervalued by providers when surgical options were presented as the primary or only treatment option. Several women felt that their provider had presented hysterectomy as the only viable treatment option, even though this option was not preferred by most women, consistent with reports that hysterectomy is often the least desired outcome, especially for NHB women (26). Although this recommendation may be clinically appropriate, participants requested a more thorough consultation that demonstrated that other options had first been explored. In some cases, participants ended their relationship with a provider if they were unwilling to discuss nonsurgical options and/or prompted them to pursue alternative wellness approaches. Seeking care from a board-certified gynecologist specializing in uterine fibroids or minimally invasive surgery may address patient concerns of goal-discordant care, however, patient access to obstetrics/gynecology (OB/GYN) and specialty care is influenced by socioeconomic status, insurance coverage, and geographic availability (6,33).

While perceptions may have been influenced by information or assessment of their condition that may be difficult to accept (eg, fibroid size is a contraindication to a minimally invasive surgical approach), several emerging themes from participant data suggest that shared decision-making around uterine fibroid care could be improved. Many participants expressed a belief that providers, especially non-OB/GYN health care providers, lacked knowledge of uterine fibroids, particularly gynecological pain and nonmenstrual symptoms, and that this negatively impacted the patient–provider relationship. This suggests that uterine fibroids should be a key topic for continuing medical education courses for primary and emergency care specialties. Early patient education on normal menstruation and potential signs of uterine fibroids may also facilitate earlier diagnosis and timely treatment for symptomatic patients. Many women could not recall their providers initiating any discussion of patient values or quality of life in discussions regarding treatment options, despite the fact that quality of life was a primary consideration in considering surgical treatment. Recall bias is a potential explanation, however, most women described experiences that occurred over multiple visits and/or were relatively recent. Women felt that providers could do more to acknowledge and take into account the emotional, cognitive, financial, and relational effects of uterine fibroids (26,34).

Greater discussion of the effectiveness and therapeutic goals of treatments, including oral contraceptives and lifestyle/alternative approaches, may promote a greater understanding of treatment options—including the quality of evidence supporting their use—and avoid the perception that they are being unduly directed toward surgery. The use of specialized encounter-based decision aids as has been frequently developed for methods of contraception may assist patients in active participation in a shared decision-making process. The implementation of an Option Grid™ for uterine fibroid treatment is currently being evaluated in 5 large gynecology clinics (35). Finally, perceptions of symptom dismissal, inadequate discussion of reproductive plans, patient values, treatment goals, and perceived lack of empathy often led to a breakdown of trust in the patient–provider relationship. In some instances, this lack of trust may be based on prior negative interactions with the health system, especially in the case of women of color, but was compounded by feelings of dismissal or the offer of care discordant with their own goals. Providers should be aware that patient distrust may cause some women to seek medical advice from unreliable sources, which may influence their acceptance of standard medical therapies.

Strengths and Limitations

The study's strengths include a majority demographic of NHB patients, who are historically underrepresented in medical studies. Because of social media recruitment, participants may be more active in uterine fibroid patient support and engaged in private online support groups than other women. As such, women with more negative experiences or stronger views may have been more likely to participate, although women cited varying reasons for their participation in online groups. Women who do not use social media or do not have computer/smartphone access may also have been less likely to participate. Women with lower educational attainment and on state health insurance were underrepresented in this cohort, affecting the generalizability of this data to other uterine fibroid patients. This cohort was also less likely to undergo hysterectomy than the national uterine fibroid population, which may affect views on uterine fibroid burden and treatment, including perceptions of hysterectomy (18). Additional research is needed to understand the treatment decisions of patients with state health insurance and/or women who select hysterectomy during their reproductive years. Analysis of provider views and the clinical encounter may also assist in a greater understanding of shared decision-making and communication barriers.

Conclusions

Despite the considerable impact on personal and psychosocial well-being, many participants felt that providers did not adequately take into account their lived experiences and values during the treatment process. Efforts to actively engage women in the shared decision-making process, including discussion of nonsurgical interventions, may facilitate greater patient agency and autonomy in uterine fibroid management and treatment acceptance.

Authors' Note

This study was approved by the Institutional Review Board of Mayo Clinic. All procedures in this study were conducted in accordance with the Institutional Review Board of Mayo Clinic's (17-010494) approved protocols. Written informed consent was obtained from the patient(s) for their anonymized information to be published in this article. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH.

Declaration of Conflicting Interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: KR, JBB, and MA report no conflicts of interest. EAS reports consulting for AbbVie, Bayer and ObsEva, and Myovant related to uterine fibroids and payment for development of educational content from UpToDate, Med Learning Group, PER, and PeerView. SV reports consulting for AbbVie, Myovant, and Bayer.

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Supplemental Material

Supplemental material for this article is available online.

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