

An Altered Perception of Normal: Understanding Causes for Treatment Delay in Women with Symptomatic Uterine Fibroids

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Abstract

Background: Uterine fibroids are benign tumors that are the leading cause of hysterectomy in the United States. Despite their high prevalence and associated morbidity, there are little qualitative data characterizing what drives women's treatment-seeking behavior for their fibroids.

Methods: Women with symptomatic or recently treated uterine fibroids completed in-depth interviews and demographic surveys. Interviews were transcribed verbatim and uploaded to NVivo version 10 for data management and thematic coding. Coders identified major themes and subthemes that emerged from the interviews.

Results: Sixty women ($n = 60$) completed the interviews. The kappa among coders was 0.94. The mean age of participants was 43.0 ± 6.8 . 61.7% of participants self-identified as African American, 25.0% as Caucasian, 8.3% as Hispanic, and 5.0% as Asian. Many women reported obtaining a delayed diagnosis for their uterine fibroids despite experiencing severe symptoms. There were five subthemes that identified why women delayed seeking treatment, which included the perception that their symptoms were "normal," they had a low knowledge of fibroids, they did not perceive themselves to be at risk for fibroids, they engaged in avoidance-based coping strategies, and/or they dissociated themselves from their fibroids.

Conclusions: Many women with symptomatic fibroids live with this condition chronically without seeking care. It appears that for some, limited knowledge regarding fibroids and normal menstruation may lead to a distorted view of what is normal with regard to uterine bleeding, resulting in limited treatment seeking behavior. Others know their symptoms are abnormal but simply avoid the problem. There is a need for patient-centered and community-based education to improve women's knowledge of fibroids and symptoms and to promote treatment options.

Introduction

UTERINE FIBROIDS ARE benign tumors that are present in 65% of all women by the age of 50.¹ Although benign, they can be a chronic condition for many women, as clinical symptoms may be present in up to 50% of those affected.^{2,3} These symptoms can include heavy menstrual bleeding, prolonged periods, pelvic pressure symptoms, and reproductive dysfunction.⁴ This significant morbidity during a woman's reproductive years has made fibroids the leading

cause of hysterectomy in the United States.⁵ Fibroids are also a significant public health concern, as they account for more than \$34 billion in annual treatment-related costs in the United States.⁶

There is a substantial body of research that shows the impact that fibroids have on a woman's quality of life. These tumors can lead to lost days of work, missed social events, and emotional distress.^{7,8} While limited, a few qualitative studies have assessed women with fibroids and found that the tumors can lead to severe psychosocial suffering and have an

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overall negative impact on women's health-related quality of life.⁹⁻¹¹ Despite the chronic nature of fibroids and their negative effect on women's lives, many women wait several years before seeking treatment for their tumors.^{7,12} Furthermore, there are minimal data qualitatively characterizing the perceptions and beliefs of women with fibroids to address why they continue to live with the tumors without seeking treatment.

Women's health beliefs and perceptions are vital for healthcare providers to understand, as they drive health behaviors and decision-making. While there are several models for understanding and predicting drivers of health behavior, one of the most widely used is the Health Belief Model (HBM).¹³ The HBM consists of several concepts that predict why people will take action toward a healthcare-related event: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. There are also modifying factors, including a patient's demographics, personality, and knowledge, which may also influence a patient's beliefs and/or behaviors.¹³ An understanding and acknowledgment of the perceptions and drivers of behavior are necessary when developing targeted interventions to increase engagement with the healthcare system.

The aim of the current study was to characterize reasons why women delay treatment and continue to live with this chronic condition. The findings provided in this article are part of a larger study on women with fibroids, in which more than 50 subthemes were identified. The focus of this study is on thematic content surrounding treatment delay.

Methods

Participants

A convenience sample of women was recruited from an urban academic medical center and community-based organizations between August 2013 and June 2014. Flyers that included a brief description of the study and contact information for study personnel were posted in these locations. Women were first screened *via* telephone or in person to determine study eligibility. During the screening, the study protocol was described in detail. Eligible women were between the ages of 25 and 55, had a self-reported diagnosis of symptomatic fibroids, and were English-speaking. Women who had fibroids removed greater than 12 months before the study date and women with a history of cancer were not eligible to participate. This study was reviewed and approved by the Northwestern University Institutional Review Board (IRB).

Procedures

Written informed consent was obtained from all study participants. The women then completed demographic surveys to report race/ethnicity, education level, income, and general health history. Semistructured, in-depth, one-on-one interviews were then conducted and audio recorded by one of the study investigators trained in qualitative interview techniques (M.S.G.). Each participant completed a single interview. All interviews took place in a private consultation room at the academic medical center. Recruitment for participants was ceased on observation of theoretical saturation of data.

The interview guide consisted of four sections that asked women about their pathway to diagnosis; their personal thoughts on fibroids; their experiences and knowledge concerning fibroid treatment; and any final thoughts or words of advice for other women with fibroids. Questions guided by the HBM were included in the script. Representative questions that were asked during the interview include the following:

"Once you started having symptoms, what prompted you to go to the doctor?"

"What are your thoughts about having fibroids? How does it make you feel?"

"What treatment options do you know about?"

"What advice would you give to a good friend of yours if you knew she had fibroids?"

Participants were compensated for their time with gift cards and vouchers for transportation at the conclusion of each interview.

Analysis

Interviews were transcribed verbatim by a professional transcription company. Interviews were then analyzed using qualitative data analysis by three study investigators (M.S.G., K.S.S., H.R.) trained in this technique. The qualitative analysis consisted of data collection as the initial step of analysis as opposed to first constructing a hypothesis. After data collection, the main ideas were marked by codes, which were then grouped into similar concepts. These concepts reflect the themes of the study. This data-driven strategy permits the development of inductive coding frameworks, which enable the formation of both main themes and subthemes.

The study investigators first independently reviewed a subset of interviews to identify major themes and subthemes based on repeated words and phrases, shared concepts, and similar experiences observed across the interviews. The investigators then met regularly and engaged in comparative and iterative analysis to permit consensus of the themes.¹⁴ When consensus was reached, a codebook was developed consisting of 7 major themes and 53 subthemes accompanied by descriptions and sample quotations illustrating those themes. NVivo version 10 (QSR International) was then used to assist with qualitative data management and thematic coding. A sample interview was independently coded to determine intercoder reliability across the three coders, and Cohen's kappa coefficient (κ) was determined to be 0.94. The kappa coefficient is a statistic used to measure inter-rater agreement for qualitative or categorical items, such as the themes and subthemes identified in the interviews.

Results

One hundred twenty-four women were approached or expressed interest in the study, and 60 of these women met the inclusion criteria and agreed to participate. Thirty-three of these women had some form of treatment for their fibroids in the past (including 8 women who had hysterectomies), while 27 women had no treatment at the time of the study. Regardless of treatment status, the majority of women participating in the study (50) still had symptomatic uterine fibroids. The mean age of the participants was 43.0 ± 6.8 years. Table 1 shows the sociodemographic information of the participants.

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS (N=60)

Mean ± SD (range)	
Age	43.0 ± 6.8 (29–55)
Median (range)	
No. of times pregnant	2 (1–6)
No. of children	1 (0–6)
	n (%)
Race/ethnicity	
White	15 (25.0)
Black	37 (61.7)
Asian	3 (5.0)
Hispanic	5 (8.3)
Education	
High school or GED	2 (3.3)
Some college	17 (28.3)
4-year college degree	20 (33.3)
Master's degree	16 (26.7)
Doctoral degree (MD, JD, PhD)	5 (8.3)
Annual household income	
\$0 to less than \$25,000	12 (20.0)
\$25,000 to less than \$50,000	9 (15.0)
\$50,000 to less than \$75,000	12 (20.0)
\$75,000 to less than \$100,000	5 (8.3)
≥\$100,000	19 (31.7)
Missing	3 (5.0)
Health insurance	
Yes	52 (86.7)
No	8 (13.3)
Relationship status	
Married	19 (31.7)
Single	32 (53.3)
Other	9 (15.0)

GED, General Education Diploma.

61.7% were African American, 25.0% were Caucasian, 8.3% were Hispanic, and 5.0% were Asian.

The duration of the interviews ranged from 14 minutes 44 seconds to 1 hour 9 minutes 23 seconds. The findings in this article represent a subset of the data that emerged as part of a larger study that sought to obtain an overall understanding of women's experiences living with symptomatic uterine fibroids. This article focuses on five subthemes centered on why women delayed obtaining a diagnosis for their uterine fibroids. These subthemes include an altered perception of normal, low perception of risk for fibroids, low knowledge of fibroids, an engagement in avoidance-based coping strategies, and a disconnection from fibroids.

“This is normal”—Delayed Diagnosis Due to an Altered Perception of Normal

Interviews began by asking the women to describe their journey to obtaining a diagnosis of uterine fibroids. More than one-third (37%) of the participants reported that they did not seek an immediate diagnosis despite experiencing severe symptoms. For example, when asked how long she had been experiencing heavy bleeding symptoms, one participant (#31) responded,

“Oh dear God probably at least like...I mean it was progressively worse, but I would say probably at least five years that it was just worse and worse.”

Many reasons were provided to explain participants' delay in seeking a diagnosis. Some women thought that their heavy bleeding was hereditary, while others expressed a tendency to avoid going to the physician. A minority of women also reported misdiagnosis. Of the explanations given, the most commonly cited reason for women's delayed diagnosis was the perception that what they were going through was normal. One participant (#21) said,

“...my period lasted for 30 days and it was heavy and it was horrible. I was wearing pads like the size that you get in the hospital after you have a baby and I was so used to that happening that at that time I didn't call anybody because you know it was like this is normal.”

Some women also discussed situations in which they became consciously aware that the symptoms they were experiencing were abnormal. One participant (#25) discussed her realization that the pain she felt during intercourse was not something that was normally experienced by other individuals. She explained,

“I've always had pain during sex and it was funny because Dr. _____ asked...and I was like no. And then I went home and I was like yeah, I do, but no one had ever asked me that...it never occurred to me that other people don't have pain during sex.”

“I never heard of fibroids”—Delay in Treatment Due to Limited Knowledge and Limited Perceived Risk

Women were also asked about their perceived likelihood of getting uterine fibroids before they were diagnosed. Many women responded by recalling their surprise on receiving their diagnosis, because they had never previously heard of fibroids or did not perceive themselves at risk for getting them. Nearly half of the women (48%) reported that they had no previous knowledge of fibroids. One woman (#5) explained,

“I never heard of fibroids before I had gotten them. I would have never thought that...so when the doctor told me that I was like what is that?”

Some women expressed frustration that they lacked this knowledge of the tumors. They felt that they should have known about fibroids before their diagnosis, because of the tumors' high incidence or due to later learning that they have family members diagnosed with fibroids. Some participants also mentioned that they felt personally at fault for not knowing about the tumors. Others blamed external sources such as their gynecologists or education systems for not including fibroids with other topics that are usually discussed during appointments or in anatomy or sex-education courses. When asked if she had heard of fibroids before her diagnosis, one woman responded (#1):

“No I had not. With a bachelor's degree and a master's degree in science and chemistry I had not. Thinking back to anatomy and physiology classes we talked about having babies, talked about different forms of cancer, but did they ever mention a fibroid, I don't think so.”

While half of the participants were aware of uterine fibroids before their diagnosis, about two-thirds (62%) of these women did not believe that they were at risk for being diagnosed with them. One woman (#77) mentioned:

"I was surprised when I got them...and I thought why do I have them?...my mom never had it, my grandmother never had it; nobody ever had that kind of problem so it was a first."

In contrast, women with a family history of fibroids still did not perceive themselves at risk. One participant (#3) said:

"I didn't even think about it. My mom had fibroids and so did my grandmother, but...that wasn't even something that was on my mind."

"I tell myself just suck it up"—Delay in Treatment Due to Engagement in Avoidance-Based Coping Strategies

Women were also asked how fibroids make them feel on an everyday basis, including how they managed their symptoms. Over half (55%) of the participants said that they were "just dealing" with their symptoms and engaged in avoidance-based coping strategies. Although these women experienced symptoms such as heavy menstrual bleeding and pelvic pain, they also seemed to minimize the severity of those symptoms. One participant (#16) said,

"I tell myself just suck it up and deal with it and I take my Advil and I am fine."

Some women took a practical viewpoint in an attempt to figure out the best way to live with this condition. One participant (#29) explained,

"It came and you know that was that. I just had to go on with my life. I mean things had to be done. I had to work, bills had to be paid..."

Another woman (#31) explained how she coped with her severe symptoms by stating,

"...this is what you go through as a woman and it was like every month you are going to bleed half to death and then the rest of the time you are almost okay. I just went with that...you know it didn't kill me so I would just be stronger."

"I named it the alien"—Delay in Treatment Due to Women Dissociating Themselves from Their Fibroids

Approximately one-third (28%) of the women dissociated, or distanced, themselves from their fibroids through referring to their fibroids as an "assailant," as something "alien," or as something invasive. One woman (#1) said,

"I named it the alien...just because it doesn't belong here and it needs to leave so it is the alien."

Another woman (#25) explained,

"I do kind of picture them as like, independent little beings in my uterus...I do picture them having a life of their own."

Many women explained that distancing themselves from their fibroids was a means to help them handle the extensive physical and emotional pain that they experienced because of the fibroids. One woman (#12) explained how her disconnection from the fibroids was a mechanism of coping by stating,

"I am just compartmentalizing it by having fibroids I distance myself from it because it has caused me such uncomfortableness."

Discussion

Uterine fibroids are a chronic condition for many women. While there is substantial research looking at the physical

impact of the tumors on women's lives, little is known about women's personal experiences and beliefs about their fibroids. Through using qualitative, in-depth interviews, the current study identified multiple subthemes that shed light on women's limited treatment seeking for fibroids. These subthemes include delayed diagnosis due to an altered perception of normal, perceived risk and previous fibroid knowledge, "just dealing," and disconnection. This is the first study of this type performed in a population of American women.

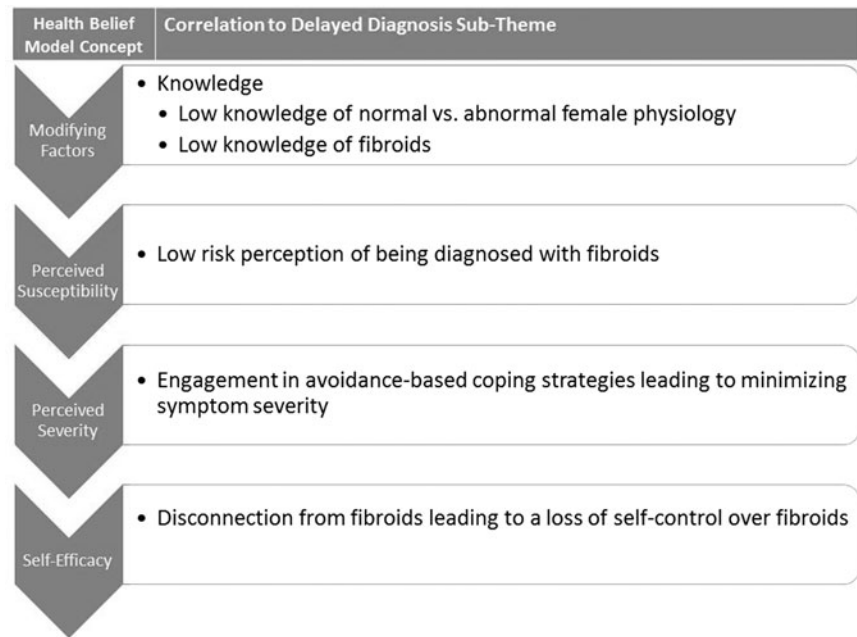
Consistent with quantitative studies, more than one-third of the women in our study reported that they obtained a delayed diagnosis of their fibroids due to delayed treatment seeking. Despite suffering from severe symptoms, most of these women did not seek an immediate diagnosis because they believed that what they were experiencing was normal. In their large quantitative survey study of U.S. women living with uterine fibroids, Borah et al. found that women waited on an average of 3.6 years after experiencing symptoms before seeking a diagnosis, and 32% waited more than 5 years before seeking treatment.⁷

The present study is novel and adds qualitative depth to these findings by showing that the primary reason *why* women delay obtaining a diagnosis is that they think that what they are experiencing is normal. These findings also confirm and add to the existing literature that demonstrates the difficulty that women with fibroids have in distinguishing between normal and abnormal female physiology.⁹ For example, one survey study found that among African American women aged 18–60, 66.8% did not know that menstrual bleeding is considered excessive/prolonged if it lasts more than 7 days and 85.5% did not know the normal length of a menstrual cycle.¹⁵

As one of the most common symptoms of fibroids, knowledge of normal menstrual patterns is vital to women's understanding of abnormal bleeding. While these studies have demonstrated women's lack of ability to identify abnormal menstruation, the present study makes a clear connection between how this altered perception of normal can directly cause women to delay obtaining a diagnosis. This connection between lack of knowledge/understanding leading to a lack of behavior is a tenant of the HBM (Fig. 1). This indicates a need for healthcare providers to educate women in both clinic and community settings regarding normal and abnormal gynecological issues so that women can take appropriate action in a timely manner. Education in community settings is particularly important as some women may not present to medical clinics for treatment, thus limiting educational opportunities.

When participants in this study received their diagnosis of fibroids, many reported surprise because they had never heard of fibroids or did not perceive themselves at risk for having fibroids.^{9,16,17} A key concept of the HBM, a distorted perception of susceptibility would be expected to and did reduce engagement in treatment seeking in our study (Fig. 1). Of those women who had no prior knowledge of fibroids (approximately half of the participants), many were frustrated by their lack of awareness of the tumors. Although previous studies confirm that there is a knowledge deficit with regard to fibroids, our study emphasizes the frustrations women feel due to lack of this information and explores where they expect to obtain this knowledge. This lack of knowledge surrounding fibroids persisted among the study sample despite it being well-educated (68.3% had at least a 4-year degree), insured (86.7% had insurance), and socioeconomically stable (60% had an annual household income of at least \$50,000).

FIG. 1. Health Belief Model concepts and the corresponding delayed diagnosis subtheme.



As with lack of knowledge on abnormal versus normal female physiology, lack of knowledge of fibroids in general also significantly impacts women's ability to take appropriate action in management of their condition. If women have no knowledge of fibroids (and subsequently their symptoms) and are unable to distinguish between normal and abnormal menstrual bleeding, they cannot be expected to seek treatment that they do not even realize they need. There is a clear need for increased discussion of uterine fibroids not only in the healthcare delivery system but also within health education curriculums.

For women who had previous knowledge of fibroids, nearly two-thirds did not perceive themselves at risk for getting the tumors. This included women both with and without a family history of fibroids. According to the HBM, perceived susceptibility is one of the key concepts affecting individual health behaviors. Using this model, if women do not perceive themselves at risk for uterine fibroids, then they are less likely to engage in behaviors to help them treat their symptoms (Fig. 1). It is vital for women to have an accurate perception of their own susceptibility to having fibroids, so that they are more apt to take action in seeking a diagnosis, and ultimately, in seeking treatment.

When it came to actually managing their symptoms, about half of the participants stated that they were "just dealing" with their fibroids and engaged in avoidance-based coping and did not seek medical help. These women also appeared to minimize the severity of their symptoms, despite experiencing heavy menstrual bleeding and severe pelvic pain. Perceived severity is another major concept of the HBM, and if women do not accurately perceive the severity of their condition, then it is less probable that they would take the appropriate actions to treat their symptoms (Fig. 1).

Nearly one-third of the women also mentioned that they dissociated or disconnected themselves from their tumors and labeled them as something other than self. Women who engage in avoidance-based coping could potentially worsen the psychological burden that these tumors have on their lives, as

avoidance-based coping has been found to increase risk of psychological distress.¹⁸ Thus, the way in which the participants minimize their symptoms and take on this avoidance-based coping style could potentially negatively impact their quality of life.

Through dissociating themselves from their fibroids and identifying them as something "alien" or "other," the women may also lose a sense of control over their uterine fibroids. Failure to accept the reality of fibroids as a real part of themselves (another avoidance-based coping strategy) may lead to the belief that they cannot do anything about them, which may lead to a sense of helplessness. Indeed, Nicholls et al. found that women who viewed their fibroids as "alien" appeared to be more distressed and anxious than women who accepted that the fibroids were a part of themselves.⁹ Within the HBM, this key construct is termed self-efficacy and refers to the confidence in one's ability to take action (Fig. 1). If women feel that they have no control or self-efficacy with regard to their uterine fibroids, then they will feel disempowered to engage in the positive health behaviors that will ultimately help them manage this chronic condition.

This study has several strengths. One strength is the racial diversity of the study sample. The majority of participants were African American women, who have a higher cumulative incidence, earlier age of onset, and overall greater burden of uterine fibroids compared to Caucasian women.^{1,19–25} We were also able to recruit women from both an academic setting and a community-based organization, which helps to more accurately represent a broad group of women's experiences with the tumors.

Another strength of the study is the sample size. Most qualitative interview studies have 10–20 participants, similar to the study by Nicholls et al., which included 18 women.⁹ The fact that we interviewed 60 women greatly increases the generalizability of our thematic findings. The study's qualitative, in-depth nature also permitted us to obtain rich, detailed descriptions of women's perceptions and beliefs that we would not be able to acquire through quantitative methods. While

quantitative studies have identified that women delayed obtaining treatment for their fibroids, the present qualitative study was able to answer why this occurs. A greater understanding of women's perceptions of their fibroids can inform healthcare professionals working with this population on how to provide the appropriate knowledge and interventions to increase women's quality of life while living with this condition.

While the present study provides a much needed perspective on why women suffer with their uterine fibroids without obtaining treatment, it does have some limitations. One limitation of the study was that a comfort level with English was required and might therefore skew our results. Another limitation is that the screening procedure relied on women's self-report of fibroids, so some misdiagnosis is possible. However, previous studies have found that self-report of uterine fibroids is accurate for >90% of women with fibroids.^{19–21} In addition, while the HBM takes into account race/ethnicity and its impact on individual beliefs, in this study, we did not specifically look at the influence of cultural factors on women's experiences with their fibroids. Some participants in our study did mention that race played a role in their experiences, and hence, further research in this area is warranted.

Conclusion

In summary, this study identifies reasons why women delay obtaining treatment for their symptomatic uterine fibroids—they have an altered perception of normal, a low perception of risk, a limited knowledge of fibroids, engage in avoidance-based coping, and dissociate themselves from their fibroids. Regardless of the reason, engagement in avoidance-based coping strategies may increase women's risk of psychological distress and limit treatment seeking. Women living with symptomatic uterine fibroids hold common and specific perceptions and beliefs about the tumors and about their own physiology, which extensively impact their treatment seeking behaviors around fibroids.

There is a significant need for both patient-centered and community-based education to inform women of normal and abnormal physiology, fibroids, their symptoms, and the range of treatment options available to them. Targeted education about fibroids specifically will hopefully increase the likelihood of accurate risk perception, symptom severity, and the utilization of treatment. By increasing women's knowledge and understanding of fibroids, healthcare providers have the opportunity to empower these women to have greater self-efficacy with regard to their care. Through utilizing multidisciplinary approaches, clinicians can greatly assist this large, yet underserved population of women.

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