



Beyond the physical: A qualitative assessment of the burden of symptomatic uterine fibroids on women's emotional and psychosocial health [☆]



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ABSTRACT

Objective: To qualitatively assess the burden of uterine fibroids on women's emotional health.

Methods: Sixty women (n = 60) with symptomatic uterine fibroids were recruited from an urban academic medical center and community-based organizations. Women completed qualitative, semi-structured interviews and demographic surveys. Interviews were recorded and transcribed verbatim. Using a grounded theory approach, three coders independently identified major themes and subthemes that emerged from the interviews.

Results: 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. Most participants exhibited a significant emotional response to their fibroids, including fear, anxiety, anger, and depression. Half of the women felt helpless and believed that they had no control over their fibroids. Many women possessed a negative self-image and cited concern over appearing less attractive, which led to difficulties becoming intimate. Several women felt that they lacked substantial support to help them deal with these issues.

Conclusion: In addition to the known high prevalence and severe physical impact of uterine fibroids, there is a significant psychological impact on women. Many women lack support to help them deal with these issues and very few seek help from a mental health professional. There is an opportunity and a need for the mental health community to address the concerns in this population, in order to improve psychological health and quality of life in patients living with this chronic condition.

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Introduction

Uterine fibroids are benign tumors present during a woman's reproductive years and are the leading cause of hysterectomy in the United States [1]. By the age of 50, fibroids have a prevalence of 65%, and that prevalence increases to closer to 90% in African-American women [2]. Although not all fibroids are symptomatic, they can be associated with heavy menstrual bleeding, which can lead to symptomatic anemia, prolonged periods, pelvic pressure symptoms, and reproductive dysfunction [3]. Despite the generally benign nature of these tumors, fibroids are a chronic disease for many women. Furthermore, fibroids are a significant public health concern as recent estimates show annual fibroid treatment-related costs to be as high as \$34 billion [4].

While many studies have assessed the physical impact of fibroids on women's health, very few have focused on the effect that fibroids have on women's emotional and psychosocial well-being [5]. When symptomatic, fibroids can significantly impact women's daily activities, leading to a lower quality of life. As a result, these benign tumors also impact women emotionally and can contribute to fears about their overall health and their ability to control their symptoms and their lives [6].

There is limited work published that qualitatively assesses women's experiences with uterine fibroids. To identify these studies, a PubMed search was performed using combinations of several terms, including "fibroids", "leiomyoma", "qualitative" and "interview". The following papers were identified. One study performed in Brazil used focus groups to identify information about women's personal impression of fibroids and found that the tumors have a negative impact on women's health related quality of life [7]. Another study conducted in the United Kingdom performed qualitative interviews with a small group of primarily Caucasian women diagnosed with fibroids. This study found that women have a wide range of experiences to try and understand the condition, the treatment options and their future health outcomes [8]. Although these studies used qualitative methods to gain a deeper

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understanding of women's experiences with fibroids, neither study had a primary focus of addressing the emotional burden caused by these tumors. To our knowledge, this is one of the first qualitative studies performed among American women who have fibroids.

Aim

The aim of the current study was to assess the emotional and psychosocial impact of symptomatic uterine fibroids on women's lives. The findings represented are part of a larger study that sought to explore and characterize women's overall experiences with uterine fibroids.

Methods

Participants

Women were recruited from an urban academic medical center and community-based organizations between August 2013 and June 2014. Women who expressed interest in the study were either screened over the telephone or in person to determine study eligibility. During the screening, the study protocol was described in detail. Eligible women had a self-reported diagnosis of symptomatic fibroids, were English-speaking and were between the ages of 25 and 55. Women who no longer had symptomatic fibroids at the time of the study, but had received treatment for their symptomatic fibroids no longer than 12 months prior to the study date were also eligible. This study was reviewed and approved by the Northwestern University Institutional Review Board.

Procedures

Before conducting interviews, written informed consent was obtained from the participants. The participants also completed a demographic survey to identify self-reported race/ethnicity, education level, household income and other information. Semi-structured, in-depth, one-on-one interviews were then conducted by one of the authors trained in interview techniques (MSG). All interviews were audio recorded and took place in a private consultation room at the academic medical center.

The interview guide was divided into four sections: the first asked about women's pathway to their diagnosis of fibroids; the second queried women's thoughts and personal experiences with fibroids; the third asked about women's experiences and knowledge concerning fibroid treatment; and the last section included wrap-up questions in which women expounded upon their fibroid experiences and offered advice to other women with fibroids.

At the conclusion of the interviews, participants were compensated for their participation with a gift card. Parking or public transportation costs were also covered.

Analysis

Interviews were transcribed verbatim by a professional transcription service. Following transcription, the interviews were thematically coded for emergent themes using a grounded theory approach. This method is a systematic data-driven strategy in which the first step is data collection as opposed to the formulation of a hypothesis. Following collection of the data, key points are marked with codes and these codes are then grouped into similar concepts. Categories or themes are then determined from those concepts. This strategy allows for the creation of entire inductive coding frames, comprising both main categories and subcategories. Using a grounded theory approach, three members of the research team trained (MSG, KSS, HR) in qualitative data analysis independently reviewed a sample of interviews and identified major themes and sub-themes that emerged through repeated words, phrases

and discussions of behaviors and experiences [9,10]. These members of the research team met regularly to review and discuss the analysis, allowing for refinement of themes with each iteration of analysis. After consensus was reached regarding the themes, a codebook was then developed, which included theme descriptions and quotes from interview text that exemplified the themes. The codebook included a total of 7 major themes and 53 sub-themes, four of which are the focus of this manuscript. Interview transcriptions were then uploaded to NVivo version 10 (QSR International) for data management and thematic coding. To determine inter-coder reliability, a sample interview was independently coded using the developed codebook by three members of the research team. NVivo was employed to compare the coding of this interview across the three researchers and Cohen's kappa coefficient (κ) was calculated to be 0.94. Data from the demographic surveys were entered into a database and analyzed using the Statistical Package for the Social Sciences (SPSS) version 18 (Chicago, IL).

Results

One-hundred twenty-four women were approached or expressed interest in the study, of which 60 met the inclusion criteria and agreed to participate. A total of 35 h of interviews were conducted, yielding 1357 transcribed pages. Table 1 summarizes the socio-demographic information of the participants. Thirty-seven (61.7%) African-American, 15 (25.0%) Caucasian, 5 (8.3%) Hispanic and 3 (5.0%) Asian women participated. The mean age of all women was 43.0 ± 6.8 years. Fig. 1 shows participants' self-reported physical symptoms and psychosocial burden caused by their fibroids.

As previously mentioned, the data presented in this manuscript emerged as a part of a larger study, which sought to gain an understanding of women's overall experiences with fibroids. In this manuscript, we report on the four sub-themes that specifically reflected women's emotional and psychosocial responses to living with uterine fibroids. These sub-themes included psychological distress, helplessness, negative body image and sexuality, and lack of support.

"Am I dying, God am I dying?"

We asked women to describe their initial reactions and feelings toward their fibroid-related symptoms before they were diagnosed with fibroids. Ninety-five percent of the women expressed that their fibroids caused significant psychological distress on their

Table 1
Demographic characteristics of participants (N = 60).

Mean \pm SD (range)	
Age	43.0 \pm 6.8 (29–55)
Median (range)	
Number of times pregnant	2 (1–6)
Number 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)
\geq \$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)

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