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Racial/Ethnic Differences in Women's Experiences with Symptomatic Uterine Fibroids: A Qualitative Assessment

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Abstract

Objective—To determine racial/ethnic differences in treatment experiences and expectations among women with fibroids.

Methods—Sixty women with symptomatic uterine fibroids completed semi-structured interviews, demographic surveys and a health literacy assessment. Participants were recruited from community-based organizations and health care organizations. Data from interviews were analyzed using a grounded theory approach. Three coders identified major themes and subthemes.

Results—The kappa (κ) amongst coders was 0.94. The mean age of participants was 43.0 ± 6.8 (mean $\pm$ SD). 61.7% of subjects were African-American (AAW), 25.0% were Non-Hispanic White (WW), 8.3% were Hispanic (HW) and 5.0% were Asian (ASW). When considering treatment options, AAW were more likely to want a permanent intervention. They were also more likely to demonstrate an aversion toward conventional treatments. Of the women who received a surgical intervention, AAW were also more likely to have had a difficult recovery and to be dissatisfied with their treatment. Finally, AAW disproportionately expressed concern regarding financial challenges.

Conclusions—AAW have high treatment expectations, have more financial obstacles, and are less satisfied with their treatment outcomes than women of other racial/ethnic groups. Our findings suggest a need to create targeted patient interventions and education to ameliorate these disparities in experience.

Keywords

fibroids; health disparities; qualitative; interviews; race

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Disclosure of potential conflicts of interest

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Introduction

Leiomyomas, or fibroids as they are more commonly known, are benign, sex-steroid sensitive tumors that are present during a woman's reproductive years. Fibroids affect up to 65% of all women by the age of 50, but the prevalence is closer to 90% in African-American women (AAW) [1]. Although not all fibroids are symptomatic, up to 20–50% of women affected can experience sequelae which include pelvic pressure or pain, reproductive problems, depression and emotional problems and heavy menstrual bleeding that can lead to anemia [2, 3]. As a result, uterine fibroids are the leading cause of hysterectomy in the United States and a serious public health issue. Recent estimates show they are responsible for up to \$34.4 billion in costs annually [4, 5].

Although a significant public health concern, few studies have looked specifically at health disparities related to fibroids. These studies have shown that African-American women have a higher cumulative risk, earlier age of onset, more severe symptoms and overall greater burden of fibroids as compared to white women [1, 6, 7]. Compared to white women (WW), African-American women (AAW) have a higher prevalence of clinically significant fibroids, 50% versus 35% [1, 8]. In addition, African-American women have twice the rate of hysterectomy for their fibroids compared to white and Hispanic women [9]. A recent online survey study of women with symptomatic uterine fibroids found that African-American women were more likely to experience symptoms longer before seeking treatment, have more treatment related concerns, and experience difficulty finding information on the risks and benefits of different treatments [7]. While these studies were able to gain knowledge surrounding women's prevalence of and experiences with fibroids, their quantitative nature did not permit for answering the "why" behind many of the racially disparate findings. The purpose of this study was to use qualitative methods to determine racial/ethnic differences in treatment experience and expectations among women with fibroids.

Materials and Methods

Participants

Women were recruited from an academic medical center and community-based organizations. Women who expressed interest in the study were screened in person or over the telephone to determine eligibility. The study protocol was described in detail at the time of the screening. Eligible women were English-speaking, between the ages of 25–55 years, and either reported a current history of symptomatic uterine fibroids or received surgical treatment to remove their symptomatic fibroids within the past year. This study received approval from the Northwestern University Institutional Review Board.

Procedures

Written informed consent was obtained from all study participants prior to conducting interviews. Women also completed a demographic survey that included: race/ethnicity, education level, household income, and health insurance status. One of the study investigators trained in qualitative interview techniques conducted semi-structured, one-on-one interviews with study participants (MSG). These interviews took place in a private

consultation room, and were audio recorded and transcribed verbatim by a professional transcription company. All interviews were structured around a guide that asked women about their pathway to their diagnosis of fibroids, their personal thoughts and feelings about fibroids, any treatment experiences related to their fibroids, and any advice they would give to women currently living with fibroids. At the completion of the study, all participants took the Rapid Estimate of Adult Literacy in Medicine- Short Form (REALM-SF), a health literacy assessment. When interviews were completed, participants received gift cards and transportation vouchers as compensation for their time.

Analysis

Three study investigators trained in qualitative data analysis (MSG, KSS, HR) employed a grounded theory approach to thematically code the content of the interviews. The first step in this method involved data collection as opposed to the traditional initial step of developing a hypothesis. Following data collection, codes were applied to the interview text in order to mark significant concepts. These concepts were then grouped into major themes, allowing for the development of inductive, open-ended coding frames. Using this method, a sample of interviews were independently reviewed by the study investigators. Major themes and subthemes were drafted by these investigators through identifying shared experiences and repeated words and phrases used across the interviews. The investigators then met regularly and engaged in iterative analysis to refine the themes. When consensus regarding the themes was reached, a codebook was developed, consisting of 7 major themes and 53 subthemes. Each theme and subtheme was accompanied by a definition and an exemplary quotation representing that particular theme. A single sample interview was then independently coded by three study investigators (MSG, HR, GM) in order to determine inter-coder reliability (Cohen's kappa coefficient). The remaining transcripts were divided among those three researchers for coding. A qualitative data analysis software program (NVivo version 10, QSR International) was used to assist with coding and data management. Data from the demographic surveys was analyzed using the Statistical Package for the Social Sciences (SPSS) version 18 (Chicago, IL). This paper focuses on four subthemes that demonstrated racial/ethnic disparities.

Results

One hundred twenty-four women expressed interest in the study. Sixty women were eligible and participated. The 60 conducted interviews resulted in a total of 35 hours of audio recordings and 1357 pages of transcribed material. Cohen's kappa coefficient (κ) was calculated to be 0.94. Table 1 summarizes the socio-demographic data of the participants. The mean age of all women was 43.0 ± 6.8 years. Thirty-seven (61.7%) women were African-American (AAW), 15 (25.0%) were white (WW), 5 (8.3%) were Hispanic (HW) and 3 (5.0%) were Asian (ASW). 68.3% of the participants had at least a Bachelor's degree and 86.7% had health insurance. There were no significant differences in annual household income or education level across race/ethnicity.

Four major subthemes with notable racial/ethnic differences emerged as women discussed their experiences with having fibroids. Differences in the following subthemes were

identified: 1) treatment expectations, 2) treatment barriers, 3) financial challenges, and 4) treatment recovery and satisfaction.

Treatment Expectations

Women who had not yet received treatment for their uterine fibroids (45%) were asked what information they felt that they still needed in order to feel comfortable about making a treatment decision. Some women said that they wanted a guarantee that the treatment would work or that it would be a quick and permanent fix. All of the women who made these statements were AAW. For example, one AAW (#6) said,

“I want to be reassured that there is a procedure that is going to work...I don’t want to have a procedure done twice...I just don’t want to go through two surgeries. I don’t want it to keep being a problem. I don’t want something just temporary.”

Despite wanting a treatment plan that guaranteed definitive treatment of their fibroids, AAW were less interested in definitive surgical management.

Treatment Barriers

Participants were also asked if there were any challenges or barriers standing in the way of obtaining treatment. Some women mentioned that they avoided taking medication and going to see their physicians. Of these women, AAW were much more likely than women of other racial/ethnic groups to express an aversion toward taking medications. One AAW (#88) explained,

“Because I don’t like taking drugs. Ever since I had the pulmonary embolism drugs, they almost killed me... so I just decided I don’t want to put drugs in my body.”

While AAW were more likely to be very averse to any conventional treatment options (medical or surgical), WW, in comparison, were more likely to opt for surgical management. One WW (#84) said,

“Well for me I don’t know how long I had it before I felt it so it didn’t really bother me, but once I felt it I just wanted to have it removed or have it go away...”

Financial Challenges

When women were asked about the impact fibroids had on their lifestyle, over one third discussed finances. Several women cited monetary difficulties in keeping up with the cost of hygiene-related products. All of these women were AAW. One AAW (#1) shared,

“Buying Depends, which are very expensive, and also tampons and pads, more than usual. I probably spend \$100 [a month] on that stuff they’re not cheap at all.”

Another financial challenge that participants discussed was the problem of insurance. Fifty-two women (86.7%) in the study reported having health insurance. However, among the women who reported financial challenges with managing their fibroids, the majority of these women reported insurance related challenges. Women were concerned about the cost of diagnostic testing and the cost of surgery. All of these women were AAW. Furthermore,

inadequate coverage created an emotional weight common amongst women of all racial/ethnic groups. An ASW (#28) expressed,

“...financially, it’s draining because just thinking about this. I’m supposed to have surgery for this right now and my insurance doesn’t cover 100%. It only covers 80% so the 20% is kinda stressing me out because I’m on short-term disability so I’m not getting paid like 100%.”

However, AAW disproportionately reported having inadequate coverage or lacked insurance (75%) compared to other women in the study- 15% white, 5% Hispanic and 5% Asian. For many, lack of sufficient coverage ultimately hindered them from receiving treatment. One AAW (#57) shared,

“...at the time that I realized I really needed a procedure I didn’t have coverage for it, I was underinsured.”

Those who were precluded from treatment due to inadequate coverage had similar shared experiences to those that lacked insurance. An AAW (#16) reflected,

“...but I never took care of it because I didn’t have insurance...I would like to have them taken out of me now, but of course it is not happening because I don’t have insurance. I hate the heavy periods, I hate them with a passion and it’s not just the periods- it is the cramps. The cramps are so intense right now it is not even funny... it is hard for me to move around, get out of my car.”

Treatment Recovery and Satisfaction

Thirty-three (55%) of the women who participated in this study received a myomectomy, uterine artery embolization and/or a hysterectomy for their uterine fibroids. A significant minority of these women reported that they experienced a difficult recovery process following their treatment. Of those women, AAW were much more likely to report a difficult recovery process compared to women of other racial/ethnic groups. One AAW (#39) said,

“It was kind of emotionally difficult this last recovery process. I just felt so vulnerable because I couldn’t do much, like I really needed a lot of assistance...it took maybe six to eight weeks to heal. You just don’t know how much you use the muscles in your stomach...so the recovery process was very difficult.”

Women of other racial groups were much more likely to report a good recovery. For example, one WW (#56) said,

“Recovery is going pretty good...this Thursday it will be four weeks, but I definitely feel so much better.”

Women who received interventions for their fibroids were also asked how satisfied they were with their treatment. AAW were more likely to be unsatisfied with their treatment and its outcomes as compared to WW, HW and ASW. Elaborating on her experience, Participant #39 shared,

“I was like why is this taking me six months to a year for me to really feel 100%. I was upset, especially if there could have been some alternative treatment.”

In contrast, women of other racial/ethnic groups were much more likely to report being satisfied with their treatment choice. One HW (#4) explained,

“I was really satisfied [with the treatment]...I mean the results were great and it was short so I couldn’t really complain about that.”

Discussion

Our data suggest that health disparities exist in the management and treatment *experience* of women with fibroids. Through semi-structured qualitative interviews, we identified themes and subthemes that revealed disparities in the following areas: treatment expectations, treatment barriers, financial challenges, and treatment recovery and satisfaction. Uterine fibroids significantly impact women of all races but disproportionately impact African-American women, with almost 90% having fibroids by age 50 [1, 6, 8, 10]. Several studies have reported on the clinical and epidemiologic factors relating to race/ethnicity and fibroids. Very little research, however, has been done to identify disparities in the subjective experience of women as they seek treatment for this chronic disease. Our study revealed a contradiction between AAW expressing a desire to be cured yet also expressing an aversion toward conventional treatment. The reason for this paradox is unclear. It may be a reflection of a limited medical understanding of what it takes to truly cure disease versus simply treating symptoms. However, it may also reflect an individual’s cultural objection or internal conflict associated with particular treatment options, as observed in patient decision-making in other medical conditions [11–13].

We also found that women across all racial/ethnic groups discussed financial challenges associated with their fibroids. AAW, however, disproportionately discussed challenges with inadequate health insurance coverage as compared to women of other racial/ethnic groups. Previous studies have examined the direct and indirect costs of fibroids at the national level, however few have examined this burden at the individual level [4, 5, 14]. Our study not only revealed the continued insurance challenges that women with fibroids experience but also highlights their day-to-day cost as demonstrated by the comments that women made about paying for costly hygiene related products and diagnostic testing. This study was done prior to the implementation of many of the Affordable Care Act (ACA) reforms, so it remains unclear to what extent the insurance burden will persist going forth.

Finally, while more than half of the women who participated in the study received treatment, AAW reported having a difficult recovery and more treatment dissatisfaction than their racial/ethnic counterparts. It is unknown why this was the case. However, it could be due to AAW having a more severe disease burden compared to women from other racial/ethnic groups or it could be related to differences in the type of treatment received. For example, one would anticipate different recovery outcomes in women who undergo abdominal (open) surgery versus women who undergo a non-invasive procedure or a minimally invasive surgery. In fact, previous studies have shown that racial minorities are more likely to undergo abdominal hysterectomy than laparoscopic or vaginal in comparison to WW [15, 16]. As a result, ease of recovery and satisfaction of treatment may be affected.

While the racial/ethnic differences observed in this study provide valuable information on understanding the fibroid experience, our findings should be interpreted in the context of several limitations. We did not specifically look at the severity of disease at the time of diagnosis, which without question influenced the counseling that patients received. The purpose of this paper, however, was not to determine if the recommended treatment was necessarily *appropriate*, but was to understand if women *perceived* that the treatment was appropriate based on race. While as a whole this is a large study for a qualitative study, the smaller numbers in our racial/ethnic subgroups preclude us from making definitive conclusions. Additional studies will be needed to confirm our findings. Another limitation is recall bias. We acknowledge women's recollection of their symptoms, path to diagnosis and recovery process after treatment is impacted by their overall satisfaction or lack thereof. Lastly, in regard to the financial challenges women discussed, this study was done prior to the major insurance changes related to the ACA. As such, the findings of the study may not be as generalizable to the current population of women affected by fibroids. A major strength of this study is its qualitative nature. While there has been quantitative research done on the experience of women with fibroids, there still remains a need for deeper understanding of these experiences to better support existing patient care models. Another strength is the diversity of the sample. The majority of the participants were AAW, which is more reflective of the population affected by fibroids. Thus, the differences we identified between AAW in comparison to their WW, HW, and ASW counterparts may better embody the population. In addition, the study also utilized women from the community and an urban academic center which created the opportunity for a more comprehensive perspective of women's experiences. This is in contrast to previous qualitative studies that studied the experience of women with fibroids [17, 18].

Conclusion

In summary, this study demonstrated that there are racial/ethnic differences in the management and treatment experiences among women with fibroids. Although most women had concerns about their fibroid treatment counseling, AAW were more likely to report high treatment expectations, incomplete counseling, financial challenges and dissatisfaction with treatment outcomes. The data suggest that targeted patient counseling and support is warranted in this diverse patient population. It is important for physicians and patients to collaborate in order to ameliorate this challenge. One way this can be accomplished is through physicians continuing to work to understand patients' values and perspectives. In providing more comprehensive education and working to address patient concerns and misconceptions, we can advance the effort to provide equitable care in a diverse group of women and move closer to creating an ideal patient experience.

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References

1. Baird DD, Dunson DB, Hill MC, Cousins D, Schectman JM. High cumulative incidence of uterine leiomyoma in black and white women: ultrasound evidence. *Am J Obstet Gynecol*. 2003; 188(1): 100–7. doi:S0002937802714294 [pii]. [PubMed: 12548202]
2. Ghant MS, Sengoba KS, Recht H, Cameron KA, Lawson AK, Marsh EE. Beyond the physical: a qualitative assessment of the burden of symptomatic uterine fibroids on women's emotional and psychosocial health. *Journal of Psychosomatic Research*. 2015; 78(5):499–503. DOI: 10.1016/j.jpsychores.2014.12.016 [PubMed: 25725565]
3. Stewart EA. Clinical practice. Uterine fibroids. *New England Journal of Medicine*. 2015; 372(17): 1646–55. DOI: 10.1056/NEJMcpl411029 [PubMed: 25901428]
4. Cardozo ER, Clark AD, Banks NK, Henne MB, Stegmann BJ, Segars JH. The estimated annual cost of uterine leiomyomata in the United States. *Am J Obstet Gynecol*. 2012; 206(3):211 e1–9. S0002-9378(11)02353-2 [pii]. DOI: 10.1016/j.ajog.2011.12.002 [PubMed: 22244472]
5. Carlson KJ, Nichols DH, Schiff I. Indications for hysterectomy. *N Engl J Med*. 1993; 328(12):856–60. DOI: 10.1056/NEJM199303253281207 [PubMed: 8357364]
6. Marsh EE, Ekpo GE, Cardozo ER, Brocks M, Dune T, Cohen LS. Racial differences in fibroid prevalence and ultrasound findings in asymptomatic young women (18–30 years old): a pilot study. *Fertil Steril*. 2013; 99(7):1951–7. S0015-0282(13)00274-4 [pii]. DOI: 10.1016/j.fertnstert.2013.02.017 [PubMed: 23498888]
7. Stewart EA, Nicholson WK, Bradley L, Borah BJ. The burden of uterine fibroids for African-American women: results of a national survey. *J Womens Health (Larchmt)*. 2013; 22(10):807–16. DOI: 10.1089/jwh.2013.4334 [PubMed: 24033092]
8. Eltoukhi HM, Modi MN, Weston M, Armstrong AY, Stewart EA. The health disparities of uterine fibroid tumors for African American women: a public health issue. *Am J Obstet Gynecol*. 2014; 210(3):194–9. S0002-9378(13)00834-X [pii]. DOI: 10.1016/j.ajog.2013.08.008 [PubMed: 23942040]
9. Powell LH, Meyer P, Weiss G, Matthews KA, Santoro N, Randolph JF Jr, et al. Ethnic differences in past hysterectomy for benign conditions. *Womens Health Issues*. 2005; 15(4):179–86. doi:S1049-3867(05)00039-3 [pii] 10.1016/j.whi.2005.05.002. [PubMed: 16051109]
10. Marshall LM, Spiegelman D, Barbieri RL, Goldman MB, Manson JE, Colditz GA, et al. Variation in the incidence of uterine leiomyoma among premenopausal women by age and race. *Obstetrics and Gynecology*. 1997; 90(6):967–73. [PubMed: 9397113]
11. Lewis CE, Groff JY, Herman CJ, McKeown RE, Wilcox LS. Overview of women's decision making regarding elective hysterectomy, oophorectomy, and hormone replacement therapy. *J Womens Health Gend Based Med*. 2000; 9(Suppl 2):S5–14. DOI: 10.1089/152460900318722 [PubMed: 10714741]
12. Drew EM, Schoenberg NE. Deconstructing fatalism: ethnographic perspectives on women's decision making about cancer prevention and treatment. *Med Anthropol Q*. 2011; 25(2):164–82. [PubMed: 21834356]
13. Jonnalagadda S, Lin JJ, Nelson JE, Powell CA, Salazar-Schicchi J, Berman AR, et al. Racial and ethnic differences in beliefs about lung cancer care. *Chest*. 2012; 142(5):1251–8. DOI: 10.1378/chest.12-0330 [PubMed: 22700777]
14. Soliman AM, Yang H, Du EX, Kelkar SS, Winkel C. The direct and indirect costs of uterine fibroid tumors: a systematic review of the literature between 2000 and 2013. *American Journal of Obstetrics and Gynecology*. 2015; 213(2):141–60. DOI: 10.1016/j.ajog.2015.03.019 [PubMed: 25771213]
15. Abenhaim HA, Azziz R, Hu J, Bartolucci A, Tulandi T. Socioeconomic and racial predictors of undergoing laparoscopic hysterectomy for selected benign diseases: analysis of 341487 hysterectomies. *J Minim Invasive Gynecol*. 2008; 15(1):11–5. DOI: 10.1016/j.jmig.2007.07.014 [PubMed: 18262137]
16. Jacoby VL, Fujimoto VY, Giudice LC, Kuppermann M, Washington AE. Racial and ethnic disparities in benign gynecologic conditions and associated surgeries. *American Journal of*

Obstetrics and Gynecology. 2010; 202(6):514–21. DOI: 10.1016/j.ajog.2010.02.039 [PubMed: 20430357]

17. Nicholls C, Glover L, Pistrang N. The illness experiences of women with fibroids: an exploratory qualitative study. *J Psychosom Obstet Gynaecol*. 2004; 25(3–4):295–304. [PubMed: 15715028]
18. Brito LG, Panobianco MS, Sabino-de-Freitas MM, Barbosa Hde F, de Azevedo GD, Brito LM, et al. Uterine leiomyoma: understanding the impact of symptoms on womens' lives. *Reprod Health*. 2014; 11(1):10. [pii]. doi: 10.1186/1742-4755-11-101742-4755-11-10 [PubMed: 24476380]

Research involving Human Participants**1.** Statement of human rights:

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee [Northwestern University Institutional Review Board] and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

2. Statement on the welfare of animals:

This article does not contain any studies with animals performed by any of the authors.

Informed Consent

Informed consent was obtained from all individual participants included in the study.

Table 1

Demographic Characteristics of Participants (N = 60) [8]

<u>Mean ± SD (Range)</u>	
Age	43.0 ± 6.8 (29–55)
<u>Median (Range)</u>	
Number of times pregnant	
Number of children	2 (1–6)
	1 (0–6)
<u>N (%)</u>	
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)