

# The Burden of Uterine Fibroids for African-American Women: Results of a National Survey

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## Abstract

**Background:** Uterine fibroids have a disproportionate impact on African-American women. There are, however, no data to compare racial differences in symptoms, quality of life, effect on employment, and information-seeking behavior for this disease.

**Methods:** An online survey was conducted by Harris Interactive between December 1, 2011 and January 16, 2012. Participants were U.S. women aged 29–59 with symptomatic uterine fibroids. African-American women were oversampled to allow statistical comparison of this high-risk group. Bivariate comparison of continuous and categorical measures was based on the t-test and the Chi-squared test, respectively. Multivariable adjustment of risk ratios was based on log binomial regression.

**Results:** The survey was completed by 268 African-American and 573 white women. There were no differences between groups in education, employment status, or overall health status. African-American women were significantly more likely to have severe or very severe symptoms, including heavy or prolonged menses (RR=1.51, 95% CI 1.05–2.18) and anemia (RR=2.73, 95% CI 1.47–5.09). They also more often reported that fibroids interfered with physical activities (RR=1.67, 95% CI 1.20–2.32) and relationships (RR=2.27, 95% CI 1.23–4.22) and were more likely to miss days from work (RR=1.77, 95% CI 1.20–2.61). African-American women were more likely to consult friends and family (36 vs. 22%,  $P=0.004$ ) and health brochures (32 vs. 18%,  $P<0.001$ ) for health information. Concerns for future fertility (RR=2.65, 95% CI 1.93–3.63) and pregnancy (RR=2.89, 95% CI 2.11–3.97) following fibroid treatments were key concerns for black women.

**Conclusions:** African-American women have more severe symptoms, unique concerns, and different information-seeking behavior for fibroids.

## Introduction

UTERINE FIBROIDS OR LEIOMYOMAS ARE BENIGN TUMORS of the uterine muscle (myometrium) and the leading cause of hysterectomy.<sup>1</sup> Fibroids are clinically detectable in 25% to 80% of women in community-based studies; thus many women have the disease without receiving any treatment.<sup>2</sup> Little is known about the clinical burden of symptomatic fibroid disease or about the decision-making process regarding fibroid therapies.<sup>3,4</sup>

Multiple lines of evidence suggest that uterine fibroids have a disproportional effect on African-American women. African-American women have a higher cumulative risk of uterine fibroids,<sup>2</sup> a threefold greater incidence and relative risk of fi-

broids,<sup>5,6</sup> and an earlier age of onset.<sup>7</sup> In addition, African-American women are 2.4 times more likely to undergo hysterectomy and have a 6.8-fold increase of undergoing uterine-sparing myomectomy.<sup>8</sup> At the time of hysterectomy, African-American women have higher uterine weights, more fibroids, a higher likelihood of preoperative anemia, and more severe pelvic pain.<sup>9</sup> Data also suggests that African-American women may have biologically distinct disease.<sup>7,10–12</sup>

The 2011 evidence review on fibroids conducted by the United States' Agency for Healthcare Research and Quality (AHRQ) provided a comprehensive assessment of multiple areas where additional research regarding uterine fibroids is needed.<sup>13</sup> The AHRQ report included as prioritized research questions assessing the "burden of disease" and how

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“acquisition and processing of available information” allow patients and providers to “identify and choose strategies for fibroid management.” This study was designed to fill this research gap by conducting a survey in a racially diverse cohort of women with symptomatic uterine fibroids. The only prior survey of women with fibroids did not include information on race; this omission is a common problem in fibroid research and a critical one given the disproportionate impact of this disease on women of African descent.<sup>14,15</sup>

Finally, understanding the perspective of disease from the patient’s point of view is seen as increasingly important to optimize health. For uterine fibroids, obtaining this information is very timely given that uterine fibroids are one of the three high-impact research topics announced by the Patient Centered Outcomes Research Institute for 2013 (<http://www.pcori.org/2013/san-francisco-meeting/>).

## Materials and Methods

This survey was investigator designed and funded by Fibroid Relief, a program of the nonprofit Focused Ultrasound Foundation (Charlottesville, Virginia). It was conducted by Harris Interactive (Rochester, New York) between December 1, 2011 and January 16, 2012.

The methodology of the Harris Interactive online survey has been utilized and reported in a variety of medical settings, including surveys assessing awareness of cardiovascular disease in women, medication errors in geriatric patients, the impact of impaired walking ability on individuals diagnosed with multiple sclerosis, and assessment of school readiness in children diagnosed with behavioral problems.<sup>16–19</sup> The goal of the online panel is to provide a representative sample of the general population while identifying and reaching under-represented populations of interest. Panel respondents are recruited from a variety of sources, including co-registration offers on partners’ websites, targeted emails sent by online partners to their audiences, graphical and text banner placement on partners’ websites (including social media, news, search, and community portals), trade show presentations, targeted postal mail invitations, and telephone recruitment of targeted populations. Each recruitment source is carefully vetted through a rigorous interviewing and testing process and then monitored for response quality on an ongoing basis.

A weighting algorithm is utilized, which involves propensity score adjustment to minimize biases due to nonrandom selection inherent in Internet-based surveys.<sup>20</sup> Data were weighted by age, education, region, and income categories based on the March 2010 Current Population Survey data (<http://www.census.gov/cps/>) to reflect a nationally representative sample of women.

Women 29 to 59 years of age with a self-reported diagnosis of uterine fibroids and fibroid symptoms within the last two years were recruited and screened from Harris Interactive’s online panel for our survey. Exclusion criteria included women who were pregnant or breastfeeding or who had undergone a hysterectomy. Women in the sample pool who appeared to be eligible received an email briefly describing the study, and women who were interested in participating were directed to the survey website where the survey could be completed. The survey was administered in English with the goal of 1000 respondents. The Mayo Clinic Institutional Review Board determined this research to be exempt.

Race was assessed by asking “Do you consider yourself: White, African-American/African/African-American/Afro-Caribbean, Asian or Pacific Islander, Native American or Alaskan Native, Mixed race, Some other race or Decline to answer.” The respondent’s state of residence was collected and categorized in terms of the U.S. Census Bureau’s regional designations ([https://www.census.gov/geo/www/us\\_reg\\_div.pdf](https://www.census.gov/geo/www/us_reg_div.pdf)).

For symptomatic outcomes, a five-point Likert scale encompassing very severe, severe, moderate, mild, and very mild was used. Women were also allowed to report that they did not experience the specific symptom within the preceding three months. Some questions were adapted with permission from the validated Uterine Fibroid Symptoms and Quality of Life (UFS-QOL) instrument.<sup>21</sup> The five-point Likert scale of the UFS-QOL utilizes the responses all of the time, most of the time, some of the time, a little of the time, and none of the time.

Outcomes describing activity and information-seeking experiences associated with uterine fibroids were captured in a four-point Likert scale encompassing the following responses: strongly agree/somewhat agree, /somewhat disagree/strongly disagree, very important/important/somewhat important/not at all important, very concerned/concerned/somewhat concerned/not at all concerned, or very likely, likely/somewhat likely/not at all likely, as appropriate.

## Statistical analysis

Data weighted on the basis of age, education, region, and income categories are presented as mean values or percentages. Statistical comparison of continuous measures was based on the t-test of differences, and categorical measures were based on the Chi-squared test. To facilitate interpretation, the reported results were dichotomized based on whether subjects reported any of the top two categories (e.g., very severe or severe for the five-point Likert responses, and strongly agree or somewhat agree for the four-point Likert scale responses). Multivariable adjustment of risk ratios was performed using log binomial regression. In order to assess potential risk modification by age groups, marital status, income, and education on the association between race and reported outcomes, separate regression models were developed for each of these stratifications. Statistical analyses were performed using Stata SE Version 11.2 (College Station, Texas).

## Results

The survey was presented online to 140,231 women, and of these 23% (32,723) started the survey. Nine hundred and sixty-eight women or 3% of those starting the survey both were eligible and went on to complete the survey. This response rate was similar to rates in other online women’s health surveys using similar methodology.<sup>16</sup> The survey required an average of 20 minutes to complete. Fifty-nine percent of participants were white, 28% were African-American, and 12% were of other races. This study reports only on white ( $n=573$ ) and African-American ( $n=268$ ) women. so that a direct comparison based on race could be presented. Table 1 presents the demographic characteristics of the overall sample. The mean age of surveyed women was 45.25 years, and over three-quarters were in good to excellent health (74%). Most

TABLE 1. CHARACTERISTICS OF THE SURVEY POPULATION

Variable	Overall (n=841)	African-American (n=268)	White (n=573)	P Value
Age (mean in years)	45.25	43.54	46.04	0.002
Time since diagnosis (mean in months)	8.98	9.53	8.72	0.31
Employment status (%)				0.71
Employed full time	50	48	51	
Employed part time	15	13	16	
Not employed	31	34	29	
Student/retired	4	5	4	
Education (%)				0.19
High school or less	28	34	26	
Some college	34	36	34	
College graduate	24	20	27	
Some graduate school	13	11	14	
Annual income category (%)				<0.001
<\$35K	24	40	17	
\$35 - <\$50K	15	15	15	
\$50K - <\$75K	19	15	22	
\$75K or more	42	31	47	
Marital status (%)				<0.01
Never married	17	30	11	
Married/civil union/living with partner	69	53	77	
Divorced/separated	12	16	10	
Widow/widower	2	1	3	
Number of children (%)				0.98
No children	31	32	31	
Between 1b 2	46	46	46	
3 or more	23	22	23	
Overall health status (%)				0.12
Fair/poor	24	30	22	
Good	46	46	47	
Very good/excellent	29	24	32	
Age groups (%)				0.03
29-39	24	31	21	
40-49	45	47	44	
50-59	30	22	34	
Geographic locations (%)				0.001
Northeast	24	23	25	
Midwest	21	20	22	
South	35	48	29	
West	20	10	25	

Note: Survey weights are used to generate the above numbers.

women were parous and married or living with a partner (69% for both). A minimum of 20% of the sample came from each of the four geographic regions, and half of the surveyed women were employed full time (50%). Seventy-two percent had completed at least some college education, and 42% earned in excess of \$75,000 annually.

There were no significant differences between African-American and white women in our survey in employment status, education, number of children, time since diagnosis, and overall health status (Table 1). However, African-American women were significantly younger, had lower incomes, notably different marital status, and differing geographic locations.

The prevalence of specific severe or very severe uterine fibroid symptoms over the preceding three months ranged from 8% to 29%, with African-American women generally reporting higher occurrence of symptoms compared to their white counterparts (Table 2). Menstrual pain and cramps

(29%) were most commonly reported as severe, closely followed by heavy or prolonged menstrual bleeding (28%).

The adjusted risk ratios (RR) that correct for differences in baseline characteristics demonstrate that African-American women were significantly more likely to report severe or very severe symptoms compared to white women for most symptoms (Table 2). The likelihood of African-American women reporting abdominal bloating, pressure, and protrusion was two times higher (RR=2.14, 95% Confidence Interval [CI] 1.43 to 3.21), and anemia was nearly three times higher (RR=2.73, 95% CI 1.47 to 5.09) than for white women. African-American women were significantly more impacted by heavy or prolonged menses, (RR=1.51, 95% CI 1.05 to 2.18), menstrual cramps (RR=1.80, 95% CI 1.30 to 2.51), passage clots during their period (RR=1.67, 95% CI 1.20 to 2.32), and abdominal tightness or cramping (RR=1.79, 95% CI 1.21 to 2.65).

Between 14% and 22% of women felt that fibroids interfered with intrapersonal relationships. African-American

TABLE 2. FIBROID SYMPTOMS AND IMPACT ON RELATIONSHIPS AND EMPLOYMENT

Variable	Overall (n=841)	African-American (n=268)	White (n=573)	Adjusted RR (95% CI) <sup>†</sup>
<b>Symptoms (symptoms reported severe or very severe)</b>				
Abdominal bloating and pressure/protruding abdomen (%)	22	37	15	2.14 (1.43, 3.21)
Passing blood clots during your menstrual period (%)	26	40	20	1.67 (1.20, 2.32)
Heavy or prolonged menstrual bleeding (%)	28	37	23	1.51 (1.05, 2.18)
Abdominal pain/cramping/tightness (%)	24	34	19	1.79 (1.21, 2.65)
Anemia (%)	11	22	6	2.73 (1.47, 5.09)
Backache or leg pains (%)	22	28	19	1.33 (0.89, 1.99)
Constipation (%)	9	15	6	1.62 (0.77, 3.40)
Bladder symptoms (%)	9	11	9	1.05 (0.49, 2.29)
Fatigue (%)	25	32	22	1.55 (1.03, 2.32)
Menstrual pain/cramps (%)	29	42	23	1.80 (1.30, 2.51)
Painful intercourse (%)	8	10	7	1.12 (0.58, 2.17)
Lack of interest in sex (%)	18	21	17	1.15 (0.73, 1.82)
<b>Relationships (effects were felt most of the time or all of the time)</b>				
Affected your relationship with family/friends (%)	15	22	11	2.27 (1.23, 4.22)
Affected your relationship with husband/significant other (%)	22	29	19	1.42 (0.94, 2.15)
Affected your ability to take care of your home/children (%)	14	21	11	1.59 (0.98, 2.59)
Negatively affected your sense of femininity/sexuality (%)	22	25	20	1.09 (0.72, 1.65)
<b>Employment Concerns (somewhat agree or strongly agree)</b>				
Prevented me from carrying out normal work-related or professional responsibilities (%)	27	34	23	1.21 (0.71, 2.07)
Prevented me from reaching my true potential at work or in my professional life (%)	24	33	21	1.23 (0.76, 2.01)
Caused me to miss days of work (%)	29	44	23	1.77 (1.20, 2.61)
Made me afraid I'll lose my job (%)	12	21	9	2.13 (0.95, 4.76)
Prevented me from traveling for work (%)	15	24	11	1.67 (0.74, 3.78)

<sup>†</sup>Adjustment was based on log-binomial regression that accounts for the confounding factors stated in Table 1. Survey weights are used to generate the above numbers.

women were significantly more likely to experience impairment of their relationship with friends and family (RR=2.27, 95% CI 1.23 to 4.22) (Table 2). Fibroids also affected women's relationship with their "significant others" (22%) and their ability to care for their home and/or children (14%); however, African-American and white women did not differ significantly on these measures. Approximately one-fifth (22%) of all women reported feeling a negative sense of femininity or sexuality.

African-American women reported greater employment-related concerns than white women (Table 2). However, following multivariable adjustment, only the risk ratio associated with missed days of work was found to be significant. African-American women were 77% more likely to miss work than their white counterparts (RR=1.77, 95% CI 1.20 to 2.61).

Concerns regarding physical impairment due to fibroids were very common overall (Table 3). Most women (77%) were afraid of future fibroid growth, and African-American women were more likely to report this fear (RR=1.14, 95% CI 1.03 to 1.26). More than half of all women were concerned that fibroids would be associated with future health complications (61%), that they would need a hysterectomy (55%), that the fibroids would turn into a cancer (51%), that the fibroids would affect their sex life (52%), that fibroids would affect their relationship with their husbands/significant others (42%), or that their bodies would never be normal again (46%) (Table 3). However, adjusted risk ratios for these concerns were not significantly different for African-American and white women following adjustment for confounders. African-

American women were significantly more concerned that their fibroids would affect their ability to have a successful and healthy pregnancy (RR=2.05, 95% CI=1.51 to 2.78) and that their fibroids would make them depressed (RR=1.34, 95% CI 1.02 to 1.26) (Table 3).

This concern for future pregnancy was echoed in African-American women's perceptions of treatment options (Table 3). They were more likely to value a treatment option that preserved their ability to get pregnant (RR=2.89, 95% CI 2.11 to 3.97). Moreover, African-American women were more likely to view a uterine-preserving treatment option as very important than were white women (RR=2.66, 95% CI 1.76 to 4.01). Similarly, African-American women were almost three times as likely to be concerned about the effects of fibroid treatment on fertility (RR=2.65, 95% CI 1.93 to 3.63).

African-American women were more concerned about all of the queried concerns regarding fibroid treatment and had significantly more concerns than white women on almost all measures (Table 3). Most women (81%) were concerned about the invasiveness of fibroid surgery, with a significantly higher proportion of African-American women reporting this concern (RR=1.11, 95% CI 1.03 to 1.20). Postoperative pain (RR=1.12, 95% CI 1.01 to 1.23), permanence of the treatment (RR=1.24, 95% CI 1.12 to 1.37), and potential scarring (RR=1.54, 95% CI 1.32 to 1.80) also differed significantly between groups.

Overall, African-American women reported more quality of life impairment compared to white women on most queried measures, and there were also many areas where African-

TABLE 3. CONCERNS REGARDING UTERINE FIBROIDS AND TREATMENT OPTIONS AND QUALITY OF LIFE IMPAIRMENT

	Overall (n=841)	African-American (n=268)	White (n=573)	Adjusted RR (95% CI) <sup>†</sup>
<b>Concerns regarding uterine fibroids</b>				
Fibroids will grow (%)	77	84	74	1.14 (1.03, 1.26)
Other possible health complications (%)	61	67	58	1.05 (0.89, 1.23)
I am going to need a hysterectomy (%)	54	55	54	0.94 (0.77, 1.15)
Fibroids might turn into cancer (%)	53	55	52	0.95 (0.78, 1.14)
My fibroids will affect my sex life (%)	52	60	49	1.10 (0.91, 1.33)
My fibroids will affect my relationship with my husband/significant other (%)	42	50	39	1.14 (0.90, 1.45)
My body will never be normal again (%)	46	55	41	1.24 (0.99, 1.55)
Fibroids will affect my ability to have a successful & healthy pregnancy (%)	24	39	17	2.05 (1.51, 2.78)
My fibroids will make me depressed (%)	38	47	33	1.34 (1.02, 1.75)
<b>Concerns regarding fibroid treatments</b>				
Effect on my ability to have a healthy pregnancy (%)	26	45	17	2.89 (2.11, 3.97)
Effects on my fertility (%)	28	48	19	2.65 (1.93, 3.63)
Effects on my sexuality (%)	64	77	57	1.32 (1.17, 1.49)
How my husband/partner will view me (%)	36	50	30	1.56 (1.19, 2.04)
Effects on my sense of femininity (%)	49	63	43	1.44 (1.19, 1.74)
Undergoing the actual treatment (%)	78	87	74	1.15 (1.06, 1.26)
The invasiveness of the procedure (%)	81	86	78	1.11 (1.03, 1.20)
The permanence of the treatment (%)	72	84	67	1.24 (1.12, 1.37)
Potential for scaring (%)	56	74	47	1.54 (1.32, 1.80)
Number of days missed from work for recovery (%)	71	79	67	1.17 (1.03, 1.33)
Potential loss of income (%)	55	61	52	1.06 (0.81, 1.37)
Inability to take care of my family (%)	57	61	56	1.06 (0.90, 1.25)
Inability to do household chores (%)	59	67	55	1.19 (1.02, 1.39)
<b>Concerns regarding pregnancy and uterine preservation</b>				
Treatment option that preserves the ability to get pregnant in the future (%)	20	35	12	2.66 (1.76, 4.01)
Importance of uterine preserving option (%)	49	70	40	1.76 (1.47, 2.10)
<b>Questions Adopted from the UFS/QOL</b>				
<b>Energy/Mood Subscale (Effects were felt most of the time or all of the time)</b>				
Caused you to feel tired or worn out (%)	43	53	39	1.27 (1.01, 1.59)
Made you feel sad, discouraged, or hopeless (%)	19	25	16	1.19 (0.82, 1.72)
<b>Self-Conscious Subscale (Effects were felt most of the time or all of the time)</b>				
Made you feel conscious about the size and appearance of your stomach (%)	39	62	28	2.22 (1.77, 2.79)
Made you feel self-conscious about weight gain (%)	38	57	30	1.94 (1.49, 2.52)
<b>Concern Subscale (Effects were felt most of the time or all of the time)</b>				
Made you concerned about soiling clothes or bedding (%)	34	49	26	1.88 (1.42, 2.47)
<b>Activities Subscale (Effects were felt most of the time or all of the time)</b>				
Interfered with your physical activities (%)	32	45	26	1.67 (1.20, 2.32)
Interfered with your daily and social activities (%)	23	33	18	1.74 (1.21, 2.48)
<b>Control Subscale (Effects were felt most of the time or all of the time)</b>				
Made you feel as if you are not in control of your life (%)	21	26	19	1.23 (0.81, 1.88)

<sup>†</sup>Adjustment was based on log-binomial regression that accounts for the confounding factors stated in Table 1. Survey weights are used to generate the above numbers.

American women had significantly greater risk-adjusted rates of impairment (Table 3). The highest level of impairment in this sample was reported on the UFS-QOL energy/mood subscale, with 43% of women reporting feeling tired or worn out. African-American women were 27% more likely to have these complaints than white women (RR=1.27, 95% CI 1.01 to 1.59).

African-American women were significantly more likely to feel self-conscious about the size and appearance of their stomach (RR=2.22, 95% CI 1.77 to 2.79), and about weight gain (RR=1.94, 95% CI 1.49 to 2.52) (Table 3). Concerns about soiling clothes or bedding with menstrual flow was signifi-

cantly more likely for African-American women (RR=1.88, 95% CI 1.41 to 2.47). Overall, 32% of women reported interference with physical activities, with African-American women more affected than their white counterparts (RR=1.67, 95% CI 1.20 to 2.32). African-American women were significantly more likely to have fibroids interfere with daily and social activities (RR=1.74, 95% CI 1.21 to 2.48).

Forty-one percent of all women reported seeing two or more providers, and 5% reported seeing five or more providers before receiving a diagnosis of fibroids (Table 4). Women reported having fibroid symptoms for a mean of 3.7

years before seeking treatment. This interval is significantly longer for African-American women than for white women (4.45 vs. 3.34 years,  $P=0.01$ ). Moreover, significantly more African-American women wait 4 or more years before seeking treatment (42 vs. 29%,  $p<0.001$ ) (Table 4).

Before seeking treatment for fibroids, approximately 60% of all women employ over-the-counter medications to control symptoms, half (49%) employ lifestyle modification including diet and exercise, and a third (34%) utilize hormonal contraceptives (Table 4). About one quarter (26%) of all women utilize herbs, dietary supplements, or other alternative and complementary medications; this proportion significantly increases among African-American women (37 vs. 20%,  $P<0.01$ ).

The vast majority (92%) of all women received educational information about fibroids from a healthcare provider, and about half (48%) turn to health-related websites (Table 4). A

quarter of all women get information from friends or family (27%) or health brochures (22%); these two modalities were used significantly more by African-American women (36 vs. 22% for friends and family,  $P<0.004$ , and 32% vs. 18% from brochures,  $P<0.001$ ). Few women received information on fibroids from television and radio (6%), but African-American women were more than seven times as likely to utilize these information sources (14 vs. 2%,  $P<0.001$ ).

African-American women were also more likely than white women to view the fibroid information they received as inadequate (Table 4). They were significantly more likely to report needing additional information about fibroids in general (54 vs. 29%,  $P<0.001$ ), standard treatment options (59% vs. 39%,  $P<0.001$ ), alternative treatment options (58 vs. 39%,  $P<0.004$ ), and the consequences of treatment (58 vs. 37%,  $P<0.001$ ). African-American women were considerably less

TABLE 4. SEEKING A DIAGNOSIS AND INFORMATION-SEEKING REGARDING FIBROIDS

Variable (%)	Overall (n=841)	African-American (n=268)	White (n=573)	P Value
<b>Number of providers seen before diagnosis</b>				0.76
1	59	57	60	
2	26	25	27	
3	8	10	7	
4	2	2	2	
5 or more	5	6	4	
<b>Time experiencing symptoms before seeking treatment</b>				0.002
Less than 1 year	23	12	28	
1–2 Years	21	20	21	
2–3 Years	16	17	15	
3–4 Years	8	8	8	
4 years or more	33	42	29	
<b>Options for self-management of symptoms prior to seeking medical treatment</b>				
Over the counter medications	60	60	60	0.94
Exercise/Diet/Lifestyle modifications	49	48	50	0.77
Hormonal contraceptives	34	34	34	0.99
Herbs/Supplements/Other alternative and complementary medicines	26	37	20	0.01
<b>Sources of information regarding fibroids</b>				
Healthcare provider	92	94	91	0.35
Health-related websites	48	49	47	0.70
Friends and family	27	36	22	0.004
Health brochure	22	32	18	0.001
Books, magazines and newspapers	19	24	17	0.09
Internet discussion forums	16	15	16	0.94
Television and radio	6	14	2	<0.001
<b>Needs for fibroid information</b>				
Needs general information about fibroids	38	54	29	<0.001
Needs information about treatment options	46	59	39	0.001
Wants information about alternative treatments	46	58	39	0.004
Needs information about consequences of treatment options	44	58	37	0.001
Needs information about consequences of not having fibroids treated	45	53	41	0.06
Found enough useful information on internet	35	21	43	<0.001
Needs peer support	10	15	8	0.06
<b>Sources of support</b>				
Uterine fibroid website	50	60	45	0.001
Women's health website	48	59	43	0.003
General website	43	55	38	0.01
Women's health group	23	35	19	<0.001
Uterine fibroid group	21	30	18	0.001

Note: Survey weights are used to generate the above numbers.

likely to be satisfied with the information they found on the Internet regarding fibroids (21 vs. 43%,  $P < 0.001$ ).

African-American women were more likely to seek peer support than white women (15 vs. 8%,  $P = 0.06$ ), including support from uterine fibroid groups (60 vs. 45%,  $P < 0.001$ ), women's health organizations (59 vs. 43%,  $P < 0.003$ ), and general websites (55 vs. 38%,  $P = 0.01$ ) (Table 4). African-American women also generally utilized women's health (35 vs. 19%) and uterine fibroid groups (30 vs. 18%,  $P < 0.001$  for both) more often than white women.

## Discussion

Uterine fibroids are a major source of morbidity for reproductive-age women. While this statement is often repeated, the current report quantitates and articulates the magnitude of this morbidity, especially for African-American women.

This study documents that African-American women appear to report more severe symptoms and resulting functional impairment due to fibroids. Given the substantial data showing that African-American women have more objective indications of severe disease, including earlier age of onset, more fibroids, and bigger uteri, the increased symptoms and impairment they report likely result from their increased disease burden and not just racial differences in reporting.<sup>2,5,7</sup>

Moreover, the disparities are compounded at every step: African-American women are more likely to experience symptoms longer before seeking treatment. As African-American women seek treatments, they have more concerns regarding the complications and consequences of treatment options. They then find it harder to get valid information on treatment risks and benefits from a variety of sources.

The disparity in the way that uterine fibroids affect African-American women regarding fertility and pregnancy is particularly striking for two reasons. First, with an earlier onset of the disease, in their late 20s rather than their 30s on average, fibroids are more likely to have an impact on childbearing plans for African-American women.<sup>7</sup> Second, the historical issues of limiting the reproductive freedom of women of color through practices such as compulsory sterilization resonate with these findings and underlie the concerns African-American women of all ages have articulated about uterine fibroids, particularly their impact on fertility and childbearing. For some UFS-QOL outcomes, age appeared to be an effective modifier, with younger African-American women (29–39) bearing higher risks of reporting these outcomes than older African-American women. Thus, educating African-American women about appropriate fertility-preserving alternatives to hysterectomy is a key goal for clinicians.<sup>22,23</sup>

Multiple studies have demonstrated that cultural, ethnic, and educational background plays a role in a woman's selection of hysterectomy.<sup>24–28</sup> However, this is the first study to examine the effect of race on assessment of information regarding all fibroid therapies. Further studies are needed to explore patient-provider communication with African-American women. Development of decision support tools, informed by providers and patients, may help to facilitate appropriate discussions about alternative treatments. It is interesting that the highest response rate in our study came from the Southeast where hysterectomy rates have historically been highest.<sup>29</sup>

The economic impact of fibroids is also likely underestimated based on this survey.<sup>30–32</sup> A recent publication<sup>33</sup> suggested that previously reported cost for fibroids was underestimated by excluding the costs of obstetrical outcomes related to fibroids, raising costs of this disease to \$5.9–34.4 billion annually in the United States. Data on lost work productivity attributable to uterine fibroids has been limited.<sup>31,32</sup> With data from this survey demonstrating that more than one-quarter of women report lost work days and over one-fifth report concerns regarding losing their job due to the uterine fibroids, it is likely that this key parameter is substantially underestimated.

The strengths of this study are the large number of women surveyed, the use of a population-based survey to ensure that the respondents reflected the general U.S. population, and the use of the only validated measure for fibroid-specific quality of life (UFS-QOL).<sup>21</sup> Furthermore, women were drawn from the general population to reduce the bias from surveying women who have sought medical treatment. This survey substantially extends the limited data previously available by delineating the magnitude of symptoms and the specific effect of race on a variety of important parameters of disease and acquisition of information about disease and treatment options.<sup>14</sup>

Limitations of the survey include the existence of some selection bias in the overall sample due to the fact that these women participated in an online panel. That women would need Internet access and had above-average educational levels should be considered when interpreting our results. However, the use of conventional telephone surveys in the current era of smartphone use would also likely miss a substantial segment of the population. The fact that there are neither educational nor employment differences between races for women participating in this survey suggests that while the generalizability to the entire U.S. population may be affected, these specific demographic factors do not influence the racial differences.

This survey also relied on self-report of fibroids, so some misdiagnosis likely occurred. While validation of self-report has not been carried out in the subjects we surveyed, previous data suggests that self-report is accurate for over 90% of women with uterine leiomyomas.<sup>5,34</sup> Additionally, we did not administer the complete UFS-QOL instrument, so detailed assessment of QOL domains is not possible. Finally, detailed information regarding prior fibroid treatment and perceived success of earlier treatments may be potential confounders that we were unable to adjust for in the multivariate analyses.

## Conclusions

In summary, the burden of uterine fibroids is even more extensive for African-American women compared to white women than previously reported. This disparity has real-world consequences and should set the agenda for the next generation of research on uterine fibroids.

First, these findings likely have cost implications for both individuals and the healthcare system and the existing literature on costs of uterine fibroids is limited.<sup>30–33, 35–40</sup> For example, the cost of both missed work days and limitations on productivity and career advancement need to be studied to understand the true costs of uterine fibroids. Additionally, the fact that African-American women report significant delays in

diagnosis has implications for ambulatory healthcare costs and for potentially decreased efficacy of subsequent treatment due to advanced disease. A comprehensive assessment of the direct and indirect healthcare costs of this disease appears to be in order.

Understanding and addressing the needs of this population of severely affected women with uterine fibroids are key goals for healthcare providers and researchers. This substantial unmet need was recently recognized when the Patient Centered Outcomes Research Institute (<http://www.pcori.org/2012/boston-board-decisions/>) designated uterine fibroids a research priority. Key priorities for this type of research will likely include developing a severity algorithm to aid in classification of disease for research and developing user-friendly decision aids that take into account the racial differences demonstrated in this study so that all women, but especially African-American women, can have access to the best evidence in a fashion they can use most.

Last, but not least, studying treatments for uterine fibroids is critical. Hysterectomy has been the primary therapeutic tool in the gynecologic armamentarium for uterine fibroids for decades. The fact that the cumulative incidence of hysterectomy in the United States is 45%, despite the fact that only 8% of hysterectomies are performed for cancer diagnoses and 49% are for uterine fibroid and abnormal bleeding, demonstrates this overreliance on hysterectomy.<sup>41,42</sup> Moreover, there is substantial data on the regional variation of hysterectomy, with rates higher in the southeastern United States, where the relative concentration of African-American women is highest.<sup>29,43</sup> However, the strong findings related to reproductive concerns in African-American women of all ages suggests that educating this particular group about alternative to hysterectomy is especially important.

More research needs to be done regarding uterine-sparing alternatives to hysterectomy. A variety of effective techniques can be used based on the woman's symptoms, her fibroid burden, and her reproductive plans.<sup>4</sup> However, there is little comparative effectiveness research to guide therapy.<sup>13,44,45</sup> The number of randomized clinical trials (RCTs) comparing different fibroid treatments performed in the United States and those with racially diverse participants is especially small.<sup>15</sup> Although we have gained key information comparing uterine artery embolization (UAE) to surgery from RCTs performed in Europe, these studies have few women of African origin and differences in healthcare economics in Europe make their translation to U.S. populations difficult.<sup>46-48</sup> There is only one ongoing trial comparing two major interventional alternatives to hysterectomy, UAE and magnetic resonance-guided focused ultrasound surgery (MRgFUS).<sup>49</sup>

There is also evidence that at least some of the disparity related to fibroids may be due to biologic differences between black and white women, including differences in predisposition genes and environmental exposures such as vitamin D deficiency.<sup>50,51</sup> Given the high prevalence of this disease, understanding its biology in order to design early intervention or prevention strategies should be the mandate for the future.

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