

RESEARCH ARTICLE

# Differences in Fibroid Symptom Reporting among Asian and Caucasian Patients in a Multidisciplinary Fibroid Center

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**Introduction:** Uterine fibroids are prevalent in reproductive-age Asian women and can have a severe impact on health due to heavy bleeding, pelvic pain, and psychosocial harm. Current treatment, ranging from expectant management to hysterectomy, is aimed at symptom alleviation. Therefore, it is crucial for providers to accurately gauge symptom impact to determine appropriate treatments. A recent study reported differential symptom scores between Asian and Caucasian women treated at the Stanford Fibroid Center (SFC).<sup>1</sup> In this pilot study, we aim to explore potential etiologies contributing to this finding by comparing fibroid size and location, clinical factors, and surveying sociocultural factors.

**Methods:** We utilized a mixed methods approach to uncover potential associations to differential Uterine Fibroid Symptom and Health-Related Quality of Life Symptom Severity Scores (UFS-QoL SSS) between Asian and Caucasian patients at SFC. We quantitatively analyzed fibroid imaging data and clinical risk factors from this cohort and qualitatively compared semi-structured interviews in a representative sub-sample.

**Results:** We found no significant difference in fibroid size or location between groups. However, Asians had significantly lower body mass index ( $P < 0.0001$ ) and were more likely non-smokers ( $P = 0.0037$ ) compared to Caucasians. After adjusting for these and other risk factors, pretreatment UFS-QoL SSS in Asian patients were still significantly lower ( $P < 0.0001$ ). Qualitative interviews with Asian and Caucasian interviewees demonstrated comparable symptom experiences and quality of life, but more Asian participants described a negative impact from family and friends, less access to and distrust of medical providers, and pursuit of alternative therapies for their fibroids.

**Conclusion:** These findings suggest that the UFS-QoL questionnaire may be insufficient for capturing symptom burden in patients of different races. Further understanding on how the above factors modulate symptom reporting is warranted to help design appropriate fibroid treatment recommendations for diverse populations.

**Key Words:** fibroids ■ quality of life ■ race/ethnicity ■ health disparities ■ Asian health

Uterine fibroids are the most common benign neoplasm of the uterus, affecting up to 68% of reproductive-age women.<sup>2</sup> The US prevalence of fibroids in Asian women has been shown to be comparable to that in Hispanic and Caucasian women (Asian/Pacific Islander: 11.4%; Hispanic: 11.1%; White: 10.3%; Black 18.5%).<sup>3</sup> Fibroids are associated with a range of symptoms and adverse health issues, including heavy menstrual bleeding, pelvic pain, bladder pressure and dysfunction, abdominal protrusion, and

adverse reproductive outcomes.<sup>3-5</sup> Fibroid symptoms decrease the quality of life and can impact reproductive health and options. Management is largely aimed at symptom reduction and includes medical and surgical procedures. The only definitive treatment is hysterectomy, with 26% of diagnosed cases in 2015 opting for this procedure.<sup>6</sup> As these treatment options may confer significant risk, it is crucial for healthcare providers to be able to accurately gauge symptom impact in order to optimize treatment choice.

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### POPULAR SCIENTIFIC SUMMARY

- There were no significant differences in fibroid size or location between Asian and Caucasian women
- Asian women with fibroids had significantly lower BMI and were more likely to be non-smokers
- Compared to Caucasian women, Asian women described more negative impact from family and friends, less access to and distrust of medical providers, and greater pursuit of alternative therapies

The Uterine Fibroid Symptom and Health-Related Quality of Life (UFS-QoL) questionnaire is a commonly utilized metric for quantifying bleeding, bulk-related symptoms, and quality of life in patients with uterine fibroids.<sup>7</sup> Higher scores are associated with more symptom bother. Knowledge of factors that affect symptom impact is limited, but may consist of body mass index (BMI), insurance status, and previous hormonal treatment for fibroids.<sup>1</sup> Shaffer et al.<sup>1</sup> described a novel finding in which Asian women reported significantly lower symptom scores compared to Caucasian women. Since then, Murji reiterated this finding in 2020.<sup>8</sup> Given that treatment options are aimed at symptom alleviation, symptom underreporting may lead to delays in care. Racial minorities, such as Blacks and Hispanics, tend to have less trust in the healthcare system, which in turn leads to poor clinical relationships, less continuity, reduced medication adherence, worse self-reported health, and underutilization of resources.<sup>9,10</sup> However, whether distrust is associated with under-communicating fibroid-related symptoms has not been investigated. Racial and ethnic differences in fibroid-related symptom severity warrant further investigation as they may have a significant impact on access to care and treatment outcomes for Asian women.

In this pilot study, we explore factors that may affect symptom reporting including clinical risk factors, fibroid size and location, and patient sociocultural perspectives. Understanding the origin of lower symptom scores in Asian patients will allow for the development of improved assessment tools and ultimately earlier treatment for uterine fibroids in this population.

## METHODS

### Sampling and recruitment

This study was approved by the Stanford University Institutional Review Board, and consent was obtained from all interview participants.

Study participants were identified through the Stanford Fibroid Clinic (SFC), a multidisciplinary

center focused on expanding treatment options and optimizing care for women with uterine fibroids. This clinic serves patients in California and across the southwestern US. The SFC population consists of 29% Asian and Pacific Islander patients, providing a robust sample size for analyzing diseases in Asian American communities.

We used the SFC patient database, which includes over 800 fibroid patients from 2013 to 2020 including patients from April 2013 to July 2017 cohort in the Shaffer et al.'s<sup>1</sup> study, to retrospectively examine the association between clinical risk factors and UFS-QoL SSS differences between Asian and Caucasian women. The database was used to identify all premenopausal women who (1) self-identified as Asian or non-Hispanic Caucasian in electronic medical records, (2) completed UFS-QoL questionnaires, and (3) had fibroids verified on magnetic resonance imaging (MRI). We defined these patients as the 'parent population' in our study.

To qualitatively explore symptom reporting, we conducted in-depth interviews with patients who consulted with SFC between 2017 and 2020 to reduce potential recall bias. Exclusion criteria for the interviews included hormone therapy use, surgery or treatment within 8 weeks of interview, an incomplete UFS-QoL questionnaire, or pregnant state within 4 weeks of interview to avoid confounding effects on pain or bleeding. Eligible Asian and Caucasian patients were contacted via email. Participants that met all requirements and provided informed consent were interviewed by telephone. Our target sample size for the 'interview cohort' of at least 12 participants per ethnic group for a total of at least 24 participants was based on previous research suggesting thematic saturation can occur within 12 interviews.<sup>11</sup>

### Quantitative data collection and analysis

Demographic data, relevant clinical risk factors, and UFS-QoL SSS were collected from the electronic health records of eligible participants. The UFS-QoL, first published in 2002, is a validated questionnaire that is effective in identifying symptomatic fibroids and quantifying symptom severity (Spies et al.).<sup>7</sup> Fibroid data such as number of fibroids and wall position of dominant fibroid (intramural, subserosal, exophytic, or submucosal/intracavitary) were collected from pelvic MRIs attained prior to the consult visit at SFC. The volume of the dominant fibroid was calculated with the ellipsoid formula ( $L \times H \times W \times 0.52$ ).

Statistical analyses were performed using R-studio (Version 1.1.463). Data with a  $P < 0.05$  were reported as significant. Predictor variables of interest included age, BMI, smoking history, parity,

diagnosis of anemia, fibroid count, wall position, and volume of dominant fibroid. Wilcoxon rank sum test for continuous data and the chi-squared test for categorical data were employed to test the similitude between Asians and Caucasians in the parent population since a number of these measures did not have a normal distribution as prescribed by the Shapiro-Wilk test for normality. Asian and Caucasian participants in the interview cohort were compared using the Wilcoxon Rank-sum test for continuous data and Fisher's exact test for the categorical data. Bonferroni correction was used to adjust probability values for multiple comparisons in the above univariate analyses. Metrics of clinical significance including race were incorporated in a multivariate linear regression model of noncorrelated data with a Huber 'sandwich' estimator of variance to model misspecification. Linear regression was chosen because of the continuous outcome variable of UFS-QoL scale scores. Records with missing primary predictor data were excluded from the multivariate analysis ( $n = 35$  [9.7%]).

### Qualitative data collection and analysis

Eligible interview participants were invited to participate in a 30–45-min semi-structured phone interview. Participants verified demographic information from their Electronic Health Record (EHR) and were asked to self-report their racial background and generational status in the US. The interview guide, which was vetted by an obstetrician-gynecologist (BC) and qualitative researcher (JB), explored participants' presenting symptoms, knowledge about menstruation, fibroid impact on quality of life, impact from family and friends, rapport with healthcare providers, perceptions on their treatment and perceived treatment options, as well as the perception of UFS-QoL questionnaire responses. All interviews were conducted in English by NJR.

Interviews were audio-recorded, transcribed verbatim, and coded by NJR, ZD, and JN. Data analysis was facilitated using Dedoose qualitative software (Version 8.0.35). Using a priori concepts, transcripts were deductively coded and iteratively modified with input from the full research team to promote credibility.<sup>12</sup> A pooled Cohen's kappa coefficient ( $\kappa$ ) of 0.90 was achieved.<sup>13,14</sup> Once all 26 transcripts were coded, a thematic analysis was performed using an iterative and team-based theme analysis process to identify overarching themes across all interview participants and between our Asian and Caucasian subgroups.<sup>13,15</sup> Using content analysis, the number of instances in which specific sub-themes were mentioned by participants were counted and analyzed between Asian and Caucasian cohorts.<sup>12,16</sup>

## RESULTS

### Sample characteristics

Clinical risk factor data were collected from 358 SFC patients, who self-identified as Asian ( $n = 177$ ) and Caucasian ( $n = 181$ ). The parent populations were similar in age, parity, number of fibroids, volume of largest fibroid, and fibroid location. They differed significantly in their BMI, with Asians having lower average BMIs ( $-3.6$  kg/m<sup>2</sup>;  $P < 0.0001$ ), and smoking history, with Asians less likely to be current or former smokers ( $P = 0.0037$ ) (Table 1).

One hundred fifty-six patients met the inclusion criteria for interview participation. Out of the 43 participants who responded and consented for interviews, 17 were excluded due to the late discovery of an exclusion criterion or 'no show'. A sample representative of the diverse SFC population of Asian and Caucasian participants were interviewed. These were 12 Asian (7 East Asian, 2 South Asian, 3 Southeast Asian, of whom 7 are foreign born, and 4 are first- or second-generation American) and 14 Caucasian (of whom 1 is foreign born). The interview cohort mirrored the parent population in clinical risk factors and fibroid burden. Similar to the observed differences between races in the parent population, Asian interview participants' average UFS scores differed by  $-13.5$  points and BMI by  $-4.3$  kg/m<sup>2</sup> compared to Caucasian interview participants, but neither were statistically significant due to a small sample size (Table 1).

### Quantitative findings

#### Association between clinical risk factors and UFS score

Asian patients at SFC had significantly lower UFS-QoL SSS compared to Caucasian patients ( $-12.3$ ,  $P < 0.0001$ , Table 1), despite the lack of differences in fibroid bulk and location. On multivariate linear regression analysis, race and a diagnosis of anemia had a statistically significant effect on UFS-QoL SSS ( $\beta = 11.96$ ;  $P < 0.0001$  and  $\beta = 15.48$ ;  $P < 0.0001$ , respectively). An increase in BMI had a weak effect on UFS-QoL SSS ( $\beta = 0.65$ ;  $P = 0.001$ ). When Asian and Caucasians were treated as separate groups, BMI was no longer a significant risk factor in Caucasian patients and had increased significance in Asian patients ( $\beta = 0.36$ ;  $P < 0.1648$  and  $\beta = 1.28$ ;  $P < 0.0023$ , respectively; Fig. 1, Table 2). Multivariate linear regression models on these three significant factors also showed that BMI, anemia, and race had statistically significant interactions affecting UFS-QoL SSS.

#### Qualitative findings

Several key themes developed from participant understanding of their uterine fibroids including

**Table 1. Clinical and fibroid characteristics in SFC patients.**

Participant Characteristics	Parent population (n = 358)			Interview cohort (n = 26)		
	Asian n = 177	Caucasian n = 181	Adj. P	Asian n = 12	Caucasian n = 14	Adj. P
Age, years ± SD	43.1 ± 6.0	43.9 ± 6.5	1.0000	41.9 ± 7.5	46.0 ± 7.8	1.0000
BMI <sup>a</sup> : kg/m <sup>2</sup> ±SD	23.1 ± 3.5	26.7 ± 6.4	<0.0001*	22.2 ± 3.1	26.5 ± 6.3	0.4832
Diagnosis of anemia: n (%)	70 (39.5)	64 (35.6)	1.0000	2 (17)	5 (36)	1.0000
Smoking Hx: <sup>b</sup> n (%)	8 (4.7)	30 (17.0)	0.0037*	1 (8)	4 (29)	1.0000
Parity: median number of live births (IQR)	1 (0–2)	0 (0–2)	0.0995	0.5 (0–1.25)	0.5 (0–2)	1.0000
Dominant fibroid volume: median (IQR) <sup>c</sup> in cm <sup>3</sup>	142.8 (37.7–282.4)	136.25 (35.42–323.10)	1.000	159.3 (50.9– 187.2)	78.6 (33.4–327.3)	1.0000
Fibroid count			1.000			1.0000
1–5: n (%)	101 (57.7)	102 (58.0)		6 (50)	7 (50)	
6–10: n (%)	25.1 (44)	26.7 (47)		4 (33)	3 (21)	
>10: n (%)	17.1 (30)	15.3 (27)		2 (17)	4 (29)	
Fibroid wall position: n (%)			0.3044			1.0000
Intramural	132 (77.2)	134 (71.3)		8 (67)	9 (64)	
Subserosal	20 (11.7)	12 (6.9)		1 (8)	1 (7)	
Exophytic/pedunculated	9 (5.3)	20 (11.5)		1 (8)	2 (14)	
Intracavitary/submucosal	10 (5.8)	18 (10.3)		2 (17)	2 (14)	
UFS-QoL symptom severity score	44.7 ± 23.5	57.3 ± 22.2	<0.0001*	40 ± 25.1	54 ± 27.3	1.0000

\*P < 0.05 is significant.

<sup>a</sup>BMI: n = 357 [176 Asian, 181 Caucasian].

<sup>b</sup>Number of current and former smokers; n = 348 [172 Asian; 176 Caucasian].

<sup>c</sup>Right skewed distribution; n = 345 [171 Asian; 174 Caucasian].

<sup>d</sup>n = 345 [171 Asian; 174 Caucasian].

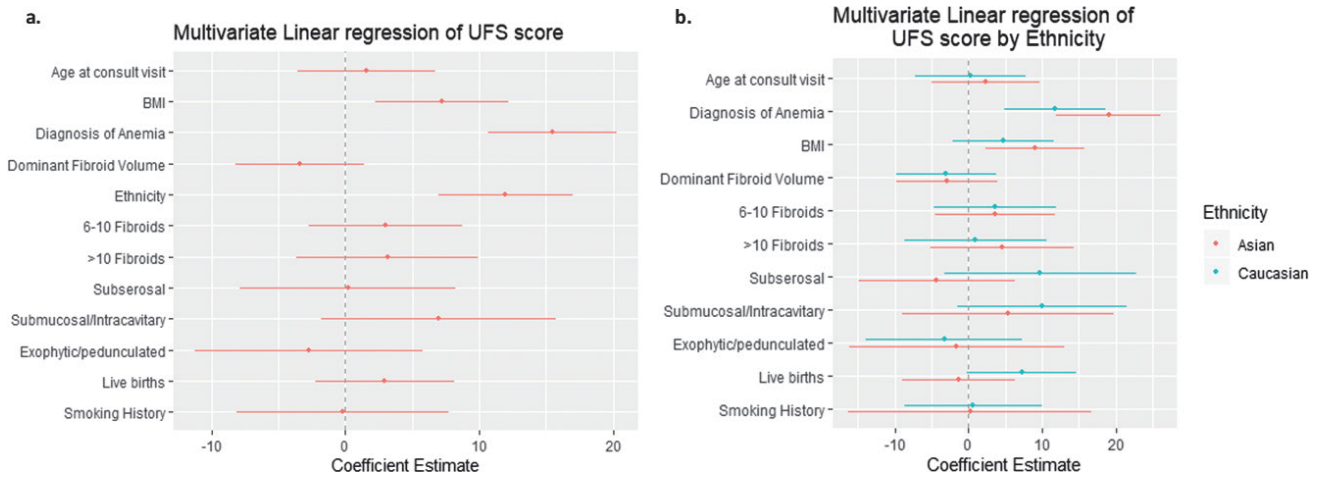
**Table 2. Multivariate linear regression on UFS-QoL SSS by common risk factors by race.**

Participant Characteristics	Asian (n = 162)			Caucasian (n = 161)		
	β-coeff	95% CI	Adj. P	β-coeff	95% CI	Adj. P
Age	0.20	-0.36–0.77	0.4917	0.02	-0.54–0.58	0.9414
BMI	1.28	0.46–2.11	0.0023*	0.36	-0.15–0.87	0.1648
Diagnosis of anemia (ref: no anemia)	19.01	12.32–25.72	<0.0001*	11.72	5.58–17.86	0.0002*
Dominant fibroid volume	-0.01	-0.02–0.01	0.3255	-0.00	-0.02–0.01	0.4348
Fibroid count (ref: 1–5)						
6–10	3.58	-3.94–11.10	0.3503	3.54	-4.41–11.49	0.3825
>10	4.53	-4.29–13.36	0.3143	0.95	-7.36–9.27	0.8211
Fibroid wall position (ref: intramural)						
Subserosal	-4.29	-14.68–6.09	0.4180	9.74	-1.41–20.89	0.0869
Submucosal/intracavitary	5.36	-8.51–19.22	0.4490	9.98	-0.41–20.37	0.0598
Exophytic/pedunculated	-1.579	-14.22–11.06	0.8065	3.28	-13.38–6.82	0.5250
Parity: live births	-0.64	-4.02–2.74	0.7118	3.33	-0.03–6.63	0.0477*
Smoking hx (ref: never smoker)	0.24	-18.16–18.64	0.9793	0.64	-7.74–9.03	0.8804
	Adjusted R <sup>2</sup> : 0.1957; P < 0.0001			Adjusted R <sup>2</sup> : 0.09587; P = 0.0057		

\*P < 0.05 is significant.

fibroid impact on quality of life, impact from family and friends, and rapport with medical providers. Across these thematic areas, we examined perceptions between Asian and Caucasian interview

participants.<sup>11</sup> We used findings from the content analysis to indicate the number of participants indicating a particular level of impact, support, or interaction with their provider.<sup>12</sup>



**Figure 1.** Multivariate linear regression of UFS score. (a) Pooled data from both groups. (b) Multivariate linear regression by race reveals BMI and diagnosis of anemia as modulators of UFS-QoL SSS in the Asian population in this study.

**Table 3.** Impact of fibroid symptom burden between Asian and Caucasian participants stratified by UFS score.

	Low (0–33; n = 9)	Medium (34–66; n = 11)	High (67–100, n = 6)
<b>Asian</b>	'My case is probably simple because there's only one big one and it's growing towards outside of the uterus, so, for a long time ...it didn't bother me'.	'You just learn to manage your symptoms. ... [menses] happens every month. I couldn't take a day off every month, like that wouldn't work out. I managed to get through the day.... because it's so regular ... You sort of learn to deal with it yourself'.	'It's just overwhelming the amount of mental anguish people experience and I just, it's not something that [can] be understood unless you've really experienced that on a daily basis, for over a year. It's just crazy ... and it wasn't really until I was on the other side of the surgery that I realized how much I suffered'.
<b>Caucasian</b>	'I didn't have any of the symptoms they described. I didn't have bleeding. I didn't have pain. I didn't have cramps. You know, I didn't have extra pressure on any organs that I could feel so, you know, it was really it was really just the...bulk'.	'I wonder if we looked earlier we would have been able to [have] done something about it ... It was at the end impacting my day to day life one of them was really big so impacting my... comfort when I was sitting down my ability to ...not run to the bathroom every hour, my ability to not be in discomfort when I was just laying down- I could feel it bulging out'.	'It definitely has changed my life in the fact that I am in bed almost bedridden a lot of the day in pain and I have to take pain pills to get through the day and sometimes I'm not able to get out of bed until 1pm because I'm in pain all day and it just comes and goes... so it's completely changed the way that I live'.
<b>Key themes</b>	Increasing	<ul style="list-style-type: none"> <li>• Disruption with sleep</li> <li>• Disruption with work</li> <li>• Rationalizing symptoms</li> </ul>	<ul style="list-style-type: none"> <li>• Anxiety provoking</li> <li>• Social isolation</li> <li>• Time spent on symptoms</li> </ul>

**Fibroid impact on quality of life**

Asian and Caucasian participants had a generally similar insight on the impact of fibroids on quality of life when stratified by low, moderate, or high UFS-QoL SSS. The most bothersome symptoms reported by both groups were bleeding and pain. When asked about their general understanding of fibroids, many women did not know what fibroids were until their diagnosis. Many participants questioned their own culpability in the development of their fibroids and others became accustomed to their symptoms over the years. Participants, particularly those with higher symptom scores, mentioned social and psychological impact including missed work and depression, which they perceived to be worse than their physical symptoms. Participants in both groups said their symptoms caused anxiety because they were unable to predict their heavy periods (or urinary urgency) because of their fibroids. Multiple participants noticed a lump or

mass, with some noting concern that fibroids made them appear pregnant, overweight, or worried over malignancy (Table 3).

**Impact of family and friends**

Overall, participants in both groups looked to their spouses and mothers for support and treatment decisions. Others found reassurance in friends who shared similar symptoms. Supportive family and friends provided comfort and reassurance and encouraged them to seek medical care (Table 4).

Nevertheless, despite feeling supported by people close to them, more Asian participants (n = 5) noted negative or unsupportive interactions with their family and friends compared to Caucasians (n = 2). Moreover, Asian participants cited different reasons why these experiences were negative, such as feeling overwhelmed or misinformed

**Table 4. Content analysis and perceptions of the impact of family and friends between Asian and Caucasian participants.**

Family/friend attitudes	Asian only	Caucasian only	Commonalities	Exemplary quote
<b>Supportive</b> <ul style="list-style-type: none"> <li>Asian, <i>n</i> = 12</li> <li>Caucasian, <i>n</i> = 13</li> </ul>	<ul style="list-style-type: none"> <li>Provided reassurance</li> </ul>		<ul style="list-style-type: none"> <li>Encouraged to see medical providers</li> <li>Included partners, mother, close female friends</li> </ul>	'[Partner] would feel it and be like "Jesus! ". Every time I would talk about it, she would be like you really need to make a doctor's appointment'. – Caucasian participant
<b>Unsupportive</b> <ul style="list-style-type: none"> <li>Asian, <i>n</i> = 5</li> <li>Caucasian, <i>n</i> = 2</li> </ul>	<ul style="list-style-type: none"> <li>No resolution</li> <li>Misinformed</li> <li>Overwhelmed</li> </ul>	<ul style="list-style-type: none"> <li>Felt let down</li> <li>Were blamed</li> <li>Loved ones expressed anxiety</li> </ul>		'Everyone's telling me something different ... this is not helpful. So ... [I] ignored it all. I just chalked it up to ... I'm getting to that age'. – Asian participant
<b>Avoidant</b> <ul style="list-style-type: none"> <li>Asian, <i>n</i> = 5</li> <li>Caucasian, <i>n</i> = 4</li> </ul>	<ul style="list-style-type: none"> <li>Does not want to scare loved ones</li> <li>Assumes lack of understanding</li> <li>Avoids negative reactions</li> </ul>	<ul style="list-style-type: none"> <li>Assumes others won't be supportive</li> </ul>	<ul style="list-style-type: none"> <li>Shame</li> <li>Won't help treatment</li> <li>Feels it is a private matter</li> </ul>	It's kind of a disgusting topic to be bleeding like that, honestly. And it made me feel very gross about myself'. – Asian participant

by family and friends. On the contrary, two Caucasian participants mentioned unsupportive interactions with family and friends, citing feeling let down or being blamed for not being able to provide for their family anymore (Table 4).

Multiple women, in particular in the Asian group (*n* = 5, Caucasians *n* = 4), felt it was inappropriate and avoided talking about their symptoms to support people (Table 4). Members of both groups did not think it would be helpful to share their perspectives with support people. Participants mentioned shame or disgust toward their symptoms and specifically in the Asian cohort, not wanting to scare family and friends.

**Rapport with medical providers**

Asian (*n* = 12) and Caucasian (*n* = 13) participants both expressed trust in their medical providers at comparable levels, but cited different reasons. Both groups described trusted knowledgeable providers, but Asians cited trust in caring and reassuring providers, while Caucasians had more positive experiences when they felt they were taken seriously, were closely followed, and were involved in decision-making. For example, one participant described feeling heard when a provider allowed her to take time to wait and see but also offered her new options when she was ready to make a change (Table 5).

Both Asians and Caucasians expressed distrust in their medical providers prior to reaching SFC. Both Asians and Caucasians cited a lack of validation from their providers, that providers had ulterior motives or were not knowledgeable, had inadequate follow-up, or had negative interactions with hospital staff. Patients in both groups expressed a desire for primary care providers to inquire more about their menstrual health. These negative interactions more often present in the Asian cohort (*n* = 9) compared to Caucasians (*n* = 7) led some participants to avoid further care, seek alternative care, and experience worsening symptoms prior to reaching SFC.

Participants in both groups cited issues with insurance and long waiting periods prior to their initial appointment with a specialist, as well as seeing multiple providers prior to reaching SFC. Notably, Asian participants (*n* = 10) mentioned problems accessing providers more often than Caucasian participants (*n* = 7). One Asian patient required an ED visit for heavy bleeding while she waited. Asian participants attributed difficulties with provider access as one of the factors for feeling less comfortable with providers (Table 5).

Multiple participants expressed frustration toward providers prior to reaching SFC for lacking treatment options. They mentioned that some of their providers were unaware of newer treatment options such as uterine artery embolization or MRI-guided focused ultrasound and instead could only provide hysterectomies or D&C. These options were very limiting, especially to those who wished to get pregnant. A significant few believed that hysterectomy was their only option for treatment. Participants cited fear of long recovery and worry over risks and complications such as decreased sex drive and infertility as factors against hysterectomy. Their fears and feelings of lack of options impeded them from getting timely treatment. Members of both groups mentioned avoiding care (4 Asians and 4 Caucasians), thinking it was not worth getting treated or normalized their symptoms (Table 5).

There were more mentions of exploring alternative therapies to conventional treatments before visiting SFC in Asians (*n* = 6) compared to Caucasians (*n* = 4). In the Asian cohort, acupuncture was most mentioned as an alternative treatment, followed by dietary changes and supplements (Table 5).

**DISCUSSION**

The UFS-QoL is a validated questionnaire that is effective in identifying symptomatic fibroids and quantifying symptom severity.<sup>7</sup> Although it was recently translated,

**Table 5. Content analysis and perceptions of rapport with medical providers between Asian and Caucasian participants.**

Attitudes toward Provider	Asian	Caucasian	Commonalities	Exemplary quote
<b>Trust</b> • Asian, n = 12 • Caucasian, n = 13	<ul style="list-style-type: none"> <li>Provides reassurance</li> <li>Prioritizes patient perspective of illness</li> <li>Compassionate</li> <li>Accommodating</li> </ul>	<ul style="list-style-type: none"> <li>Prompt communication</li> <li>Patient given autonomy</li> <li>Feels taken seriously</li> <li>Close monitoring</li> </ul>	<ul style="list-style-type: none"> <li>Provider is knowledgeable</li> <li>Multiple treatment options offered</li> <li>Provider explains treatment options and procedures</li> </ul>	'My primary care physician is fabulous ... I knew she would take me seriously... and even though it seemed like this weird grab bag of symptoms, I felt comfortable telling her about them and she helped sort it out'. – Caucasian participant
<b>Distrust</b> • Asian, n = 9 • Caucasian, n = 7	<ul style="list-style-type: none"> <li>Wasn't told of the potential side effects of treatment</li> <li>Long time to diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>Wished for more explanations, long-term planning</li> <li>Lack of reassurance</li> <li>Miscommunication between providers</li> </ul>	<ul style="list-style-type: none"> <li>Didn't feel validated</li> <li>No follow-up</li> <li>Providers were not knowledgeable</li> <li>Feels the provider had selfish motives</li> <li>Negative experience with staff</li> <li>Lack of communication</li> </ul>	I felt really pushed ... I had not heard about the treatment and it sounded so horrible. And '[gynecologist] ... dismissed it ... she felt that was the way to go but couldn't explain why. That made me suspicious... I never went back to her'. –Caucasian participant
<b>Avoidance</b> • Asian, n = 4 • Caucasian, n = 4	<ul style="list-style-type: none"> <li>Prioritize work</li> <li>Fear of pain</li> </ul>	<ul style="list-style-type: none"> <li>Worried that it will come back after treatment</li> <li>Fear that symptoms will not end after treatment</li> </ul>	<ul style="list-style-type: none"> <li>Fear of hysterectomy</li> <li>Fear of malignancy</li> <li>Nearing menopause</li> <li>Fear of surgical complications</li> <li>Long recovery time</li> <li>Not worth treatment</li> </ul>	'I was afraid of the topic because of what it might mean to me like, needing a myomectomy or hysterectomy, ... I would deliberately choose not to ask questions around that'. – Caucasian participant
<b>Limited access</b> • Asian, n = 10 • Caucasian, n = 7	<ul style="list-style-type: none"> <li>Canceled appointments</li> </ul>	<ul style="list-style-type: none"> <li>Referral issues</li> </ul>	<ul style="list-style-type: none"> <li>Long wait times</li> <li>Issues with insurance</li> <li>ED visits</li> </ul>	'I called a gynecologist ... I already had an MRI, so I know this is fibroids ... I tell them that I have been bleeding for a whole month, so I need to go in ... I'm super tired, super anemic and it's been bothering my work ... I waited almost another three weeks ... I faint thereafter ... So, I end up in the ER [needing] two units of blood'. – Asian participant
<b>Seeks alternative care</b> • Asian, n = 6 • Caucasian, n = 4	<ul style="list-style-type: none"> <li>Acupuncture</li> </ul>		<ul style="list-style-type: none"> <li>Diet changes</li> <li>OTC supplements</li> </ul>	'My focus is more like losing some weight, changing my diet and start from that. I don't know whether that has anything to do with reducing the growth of fibroids ... I believe in a more holistic concept ... I'm not sure just treating anything by itself, is the best idea'. – Asian participant

culturally adapted, and validated in Chinese,<sup>17</sup> there is no current data describing racial discrepancies with the use of the UFS-QoL questionnaire. Our previous study revealed a significant difference in UFS-QoL symptom severity scores between Asian and Caucasian women. There is scant data demonstrating differences in fibroid symptom impact among Asian women. Prior gynecological studies have shown that East and Southeast Asian women report fewer symptoms related to menopause and endometriosis relative to their prevalence, suggesting a cultural tendency to under-report symptoms compared to other ethnicities.<sup>18,19</sup> The patients in the latter report were also older and had more severe stages of endometriosis,<sup>19</sup> highlighting the need to better understand symptom under-reporting and its potential effects on under-treatment.

To further understand the racial discrepancies in UFS-QoL SSS, we sought to examine differences in clinical factors and fibroid burden between groups that may be associated with differential symptom reporting. We found

that there are no significant differences between Asian and Caucasian patients in fibroid number, size, and location, as well as parity and diagnosis of anemia. However, Asians had a significantly lower BMI and were less likely smokers than their Caucasian counterparts. Adjusting for these differences, UFS-QoL SSS continued to be significantly different between groups. In previous studies, BMI was associated with an increased risk of uterine fibroids.<sup>25</sup> Smoking, on the contrary, has been weakly linked to a decreased risk of uterine fibroids.<sup>2</sup> However, there are no publications on how these two risk factors affect fibroid symptom reporting. Curiously, this study revealed modest, but significant interactions between BMI, a history of anemia and race in predicting UFS-QoL SSS, suggesting symptom scores in Asians were more affected by changes in BMI and anemia than in their Caucasian counterparts. These observations warrant further study of this possible interaction, especially with concurrent research suggesting lower BMI cutoffs in East Asian patient risk for hypertension.<sup>20</sup>

We also qualitatively queried patient experiences to explore if this discrepancy may be cultural, environmental, or social in nature. Qualitative data were acquired from representative samples within the Asian and Caucasian populations at the SFC to maximize content saturation and methodically analyzed under current qualitative research standards.<sup>11,12</sup> Interviews suggest that patients in both Asian and Caucasian groups had similar insight in the realms of fibroid impact on the quality of life when stratified by UFS-QoL SSS, while their relationships with healthcare and their perception of support by loved ones differed.

On average, both Asian and Caucasian participants that were interviewed saw more than one provider for their fibroids before reaching the SFC, in concordance with Borah et al.<sup>21</sup> Still, more Asian interview participants reported issues with accessing medical providers either for their consultation visits or for follow-ups after fibroid treatments. More Asian participants also mentioned distrust of prior medical practitioners compared to Caucasians. Previous research has shown that distrust in healthcare, which is reportedly greater in minority groups, may be correlated with lower utilization of healthcare, which in turn may lead to a decreased sense of reliability for the medical system.<sup>10,22</sup> However, whether distrust is associated with under-communicating symptoms has not been investigated. The Asian interview cohort in this study lacked knowledgeable, accessible healthcare providers, close monitoring and treatment autonomy, bringing into question whether there is physician bias or even paternalistic tendencies from providers that should be further explored. Our findings of greater distrust among Asian patients compared to their Caucasian counterparts warrant further investigation into the impact on symptom reporting, since it has been established that distrust of physicians can alter patient narrations of illness experience.<sup>10,23</sup>

Interviewed Asian patients reported seeking alternative treatment methods more often than Caucasians. Whether alternative treatments such as diet changes, acupuncture, and supplements may play a role in reducing symptom impact or whether these patients benefit from stress relief of the perceived treatment is a subject for further exploration. Currently, there is no robust evidence for acupuncture as an effective treatment for fibroids,<sup>24,25</sup> but some studies suggest that acupuncture might reduce menstrual pain and associated symptoms more effectively than no treatment or NSAIDs.<sup>26</sup> On the contrary, the observation that more Asians tend to seek alternative treatment could suggest a lesser reliance on the healthcare system than Caucasian participants, which could result in a lower emphasis on symptom reporting to providers if less is expected of them.

This was an exploratory study to provide data for hypothesis generation. There are limitations given the descriptive nature of our study. Because the study

draws from the SFC patient population, it fails to capture patients managed by their primary care providers or gynecologists, and those who lack access to tertiary care. The interview methodology is qualitative, which is not designed to test hypotheses but rather to identify patterns across consistent themes to develop and inform hypotheses.<sup>12</sup> Furthermore, although all eligible patients were contacted, those who participated self-selected, introducing selection bias. This overall hinders our ability to make greater generalizations to women with symptomatic fibroids. Additionally, although representative of our Asian patient population as a whole, our study was not equipped to separate interview participants into the different Asian ethnic groups. This is something that should be further explored in future prospective studies as differences within this diverse group may also help explain the UFS score discrepancy. Furthermore, the cohort consisted of one immigrant from the Caucasian cohort and 11 first- or second-generation immigrants from the Asian cohort, who were all English speaking. Within the interview cohort, immigrants tended to have lower UFS scores. Taking into account first- and second-generation immigrants who may have differing views on medical interventions may be especially important since Asian immigrants are more likely to be uninsured and therefore less likely to access care than their US-born counterparts.<sup>27</sup>

## CONCLUSION

Uterine fibroids display a wide range of manifestations that underline the complexity of how the treatment is approached. Our study found that Asian patients at the Stanford Fibroid Clinic had significantly lower UFS symptom scores than Caucasian patients despite having similar fibroid characteristics. BMI, history of smoking, and race appeared to interact with UFS-QoL scores. Interviews highlighted possible issues with accessibility, provider rapport, and increased use of alternative therapies in Asian patients. These findings suggest that the UFS-QoL questionnaire may be insufficient for capturing symptom burden in patients of different races. Further understanding on how the above factors modulate symptom reporting is warranted to help design appropriate fibroid treatment recommendations for diverse populations.

## ARTICLE INFORMATION

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