



A plain language summary of the perspectives of women who were interviewed about their experiences with uterine fibroids

Elke Hunsche¹, Viatcheslav Rakov¹, Kayla Scippa², Brooke Witherspoon³ and Laura McKain^{4*}

¹Sumitomo Pharma Switzerland GmbH, Basel, Switzerland; ²Endpoint Outcomes, Long Beach, CA, USA; ³Lumina Patient-Centered Outcomes, Boston, MA, USA; ⁴Myovant Sciences, Inc., Brisbane, CA, USA

*Laura McKain was affiliated with Myovant Sciences at the time of writing this summary.

First draft submitted: 27 December 2023; Accepted for publication: 10 May 2024; Published online: 28 May 2024

Summary

What is this summary about?

This summary describes what researchers learned during interviews of women with uterine fibroids and heavy menstrual bleeding (or period bleeding). At this time, little is known about how women perceive the impact of uterine fibroids on their lives and more information is needed. The goal of this study was to provide new information about the symptoms women have and how these symptoms affect their everyday lives. These interviews were done to better understand how uterine fibroid symptoms affect the lives of women in their own words.

How to say (double click on the sound icon to play the sound)

Anemia: Uh-NEE-Mee-Uh 

Menstrual: MEN-Stroo-Uhl 

Uterine fibroid: YOU-Tuh-Ryne FY-Broyd 

What were the results?

Thirty women from the United States, who had completed a clinical trial for a new treatment for heavy menstrual bleeding and uterine fibroids, agreed to be interviewed. The women described what their experiences with uterine fibroids were and the impact these experiences with uterine fibroids had on their lives before participating in the clinical trial. The most common symptoms of uterine fibroids the women described were heavy bleeding with their menstrual periods, pain in the pelvis or groin area, the passing of blood clots, and anemia (or low hemoglobin in red blood cells). Women said their symptoms affected them physically, emotionally, socially, and financially. They also said their symptoms made it hard to do daily activities, sleep, have a sex life, and go to work or school.

What do the results mean?

Women who have heavy menstrual bleeding and uterine fibroids experience various uterine fibroid symptoms, and these symptoms affect most parts of their lives.

Who is this article for?

This summary is written to help women with uterine fibroids, their families, and their doctors understand how symptoms affect the lives of women living with uterine fibroids. The summary describes the results of an article previously published in the journal *Women's Health Reports*. The original article looked at symptoms related to uterine fibroids and how these symptoms impact women's lives. If you would like to read the original article, see the web link provided in the section:

Where can readers find more information about this study?

What are uterine fibroids?



Uterine fibroids are **non-cancerous (meaning not cancer or benign) growths** in the uterus (or womb).

About 7 out of 10 (or 70%) premenopausal women (those still having menstrual periods) **have uterine fibroids**.



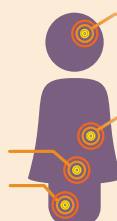
At least 1 out of 4 women with uterine fibroids have symptoms that can include:

- Heavy menstrual flow (or heavy period bleeding)
- Pain
- Fatigue (or extreme tiredness) due to low hemoglobin in red blood cells (anemia)



Because the uterus **becomes larger from uterine fibroids**, women with uterine fibroids:

- Need to pee (or urinate) more often
- Experience pain in the legs and back
- Experience pain during or after sex



The symptoms of uterine fibroids can often make it harder to work, sleep, and go to social events.

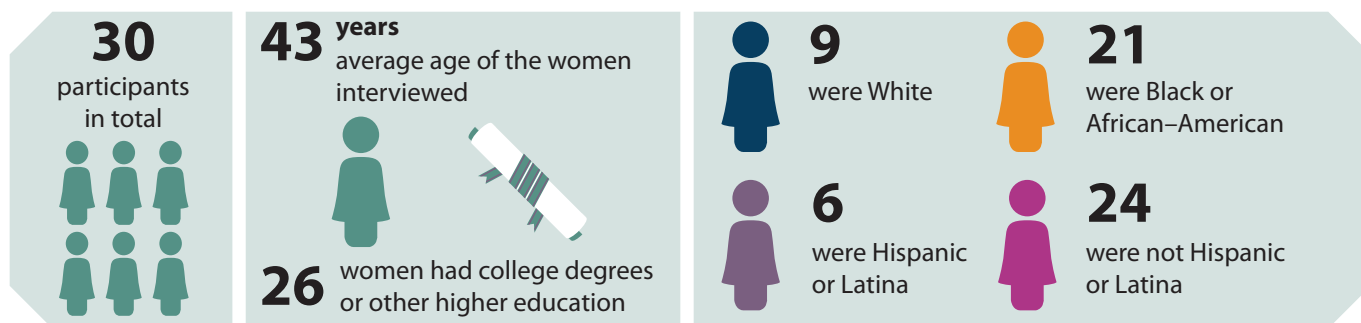
Because uterine fibroid symptoms can severely affect everyday activities, it is important to understand how the lives of these women are affected by uterine fibroids.

How were women with uterine fibroids interviewed?

- Thirty women from the United States with heavy menstrual bleeding and uterine fibroids were interviewed about their symptoms by telephone or video call.
- The interviews took place up to 14 days after the women completed the study.
- All of the interviews were in English and were audio recorded with the women's agreement.
- Researchers asked the women open-ended questions (or questions that allowed the women to give deeper answers in their own words) about their symptoms related to uterine fibroids and how these symptoms affected their lives.
- The women were able to tell the researchers how their lives were affected by their uterine fibroid symptoms in their own words.
- The women were also able to tell the researchers how uterine fibroids impact them in their own words.

Who were the women interviewed in the study?

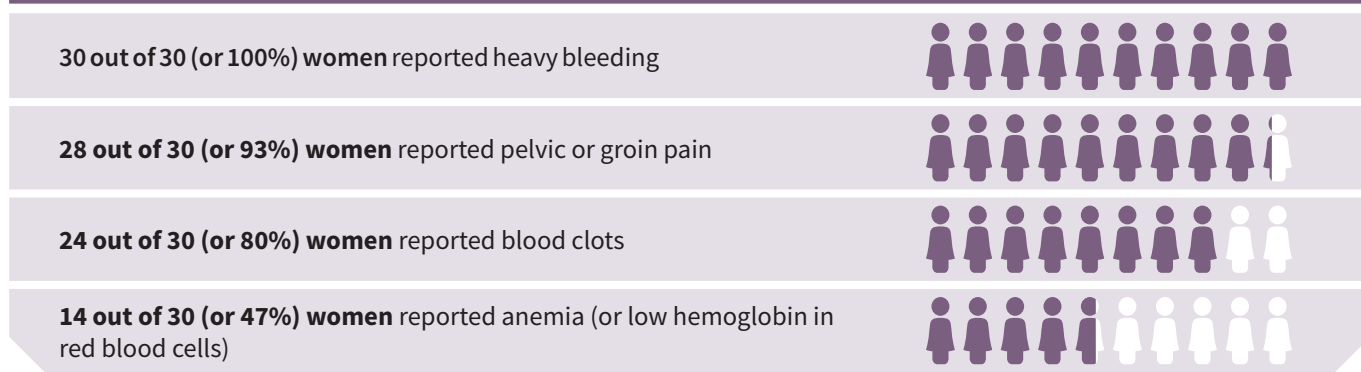
Women who were interviewed were also participants in the LIBERTY 1 or LIBERTY 2 studies, which were studies that investigated a new treatment option for women with heavy menstrual bleeding and uterine fibroids. In this interview study, researchers wanted to know how uterine fibroids impact women's lives. Participants were interviewed after they had completed the LIBERTY studies. Researchers asked them about what their experiences of uterine fibroids were before they had participated in the studies.



What were the main findings of the study?

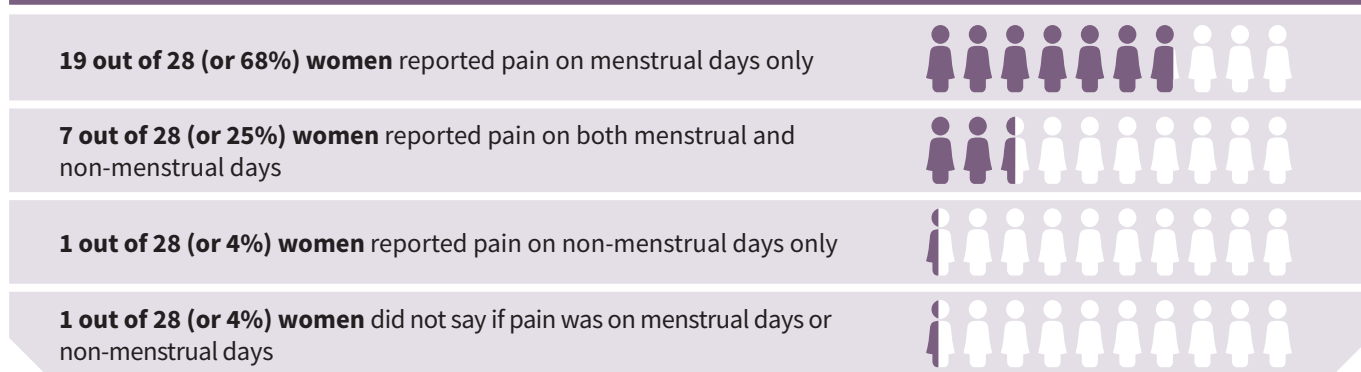
- Women had the following symptoms: heavy menstrual bleeding, pelvic pain, passing of blood clots, anemia (or low hemoglobin in red blood cells), back pain, tightness or pressure in the pelvic or groin area, bloating, headaches, urinary symptoms, leg pain, nausea (or feeling sick to their stomach), hot flushes (or a sudden feeling of warmth in the upper body usually in the face, neck and chest), chills (or a feeling of being cold and shivery), weight gain, and dizziness.

Most common uterine fibroid symptoms reported by women



- The women said the most common pain associated with their uterine fibroids was pelvic or groin pain. This pain occurred on both their menstrual and their non-menstrual days (or during their period and also not during their period).

Out of 28 women who reported pelvic or groin pain associated with uterine fibroids



Most women reported having pelvic or groin pain only on their menstrual days or everyday of their lives.

- Other types of pain the women also said they lived with on a daily basis were back pain, headaches, tightness or pressure in the pelvic or groin area, and leg pain.

How women described their symptoms of uterine fibroids

Heavy bleeding

"I developed just very heavy periods, where—you know, **soiling my clothes**—my underwear, my clothes, and my bed at night. So, I had the problem of just very heavy bleeding."

"No matter how many sanitary towels you put in, when the blood comes out, **it drains down to your feet because it pours.**"

Pelvic or groin pain

"It would be like a stabbing pain. ...like something literally is trying to rip out of me—or it's a sharp, stabbing pain. And **it would be crippling.**"

Blood clots

"I used to have clots **as big as a jellyfish**, where I could just stand up at work, like I said, and they would just fall out."

Anemia

"But then the anemia—I was very anemic, **always taking iron pills**, very tired, very—sometimes I was very, very lightheaded."

Headaches

"I would know it was coming oftentimes because I would get a headache. So, I would get the **headache knowing it [period] was coming.**"

Back pain

"So there was no bleeding but there was still pain. Like **lower back pain** or just like a sharp pain in my side."

Tightness or pressure

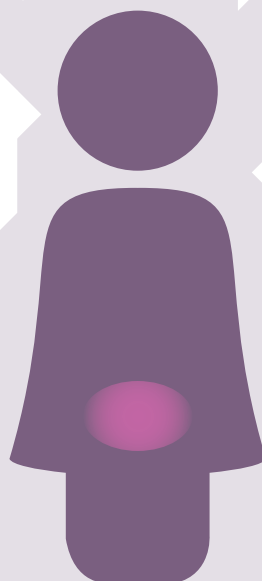
"Sometimes like my uterus just would **feel heavy, like really heavy and uncomfortable.** And there's like pressure there ... there was pressure and a heaviness in the pelvic area."

Bloating

"I get really bloated when I'm on my period and I think it's worse because of the fibroids. My belly sometimes is **so swollen I can only wear loose sweatpants.**"

Urinary symptoms (such as urgency leakage)

"Also, I would always feel like I had to urinate, **even when I didn't.**"



How women felt their uterine fibroid symptoms affected their lives

Physical effects



Tired or fatigued

“You could get a good night’s sleep, and you’ll just still feel drained all throughout the day, and you’ll just feel like you want to go lay down and go sleep. You’re just constantly tired.”

Negative impact on physical activities

“You can’t make any kind of sudden movements. Standing up hurt. Walking hurt. Sitting down is uncomfortable.”

Negative impact on exercise

“Yeah, because of the bleeding, I cannot exercise during my period, because then the flow ends up being heavier, and I practically have to break and change. The time I’m on my period, I’m not doing any exercise, I’m not doing any heavy lifting, I’m not doing any of those things.”

Stopped doing daily activities

Effects on daily activities

“When I had to clean the house and I was on my period, I wouldn’t do it. I would just wait until the week after, because it would make me [...] feel so horrible.”

Change how activities are done

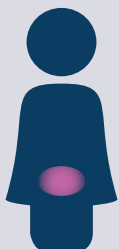
“When I’m on my period or when I know I’m going to have my period I have to shift my whole life around. I definitely don’t plan any events during my week of hell.”

Effects on downtime

“When I’m on my period, I don’t do any leisure activities. I don’t do anything fun. I just lay in my bed and wait for it to be over.”



Effects on sex



Impact on sex life

“And sex is out of the question when I’m on my period. I’m bleeding so much that I won’t let anyone near me during that time. It also has hurt in the past when I’ve tried so I just choose to avoid sex when I’m on my period.”

Impact on romantic relationships

“Yes. I would have to say I’m not in a relationship because of my uterine fibroids because I don’t care to have sex because it’s painful.”

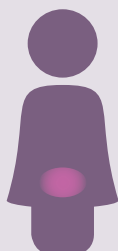
Social events

Social life issues

“Like if I wanted to go out with family or friends, I wouldn’t go, because you would be scared if you would mess up your clothes.”

How women felt their uterine fibroid symptoms affected their lives

Emotional effects



Feel embarrassed

“I think the biggest thing is the embarrassment surrounding it. It’s really embarrassing to bleed through your clothes in public.”

Feel worried or anxious

“I am always worried that it is going to get worse and I’ll be even more limited than I already am.”

Feel sad or depressed

“I would get depressed because I couldn’t really do anything. I didn’t understand what was going on in my body.”

Fear of bleeding through clothes

“I was afraid that I’d get blood all over myself in public and that they would notice I was bleeding.”

Feel angry or irritable

“I would be—get angry, so I’m constantly irritated. And I was always irritable. Irritable because I’m spotting, like this will not go away.”

Impact on finances

Financial effects

“Financially the cost of buying a lot of pads and not just pads but Depends and Poseys (brand names of sanitary products available in the US)—the Poseys and going through all that pain medication and iron tablets and vitamins—yeah, it affected me.”

Work or school issues



Loss of productivity or limited at work or school

“I mean before when I would go into work, I certainly wasn’t as efficient. I like to think I’m good at my job. When I’m on my period, it gets in the way of me being able to do my job.”

Missed work or school

“Yes, because I haven’t been working this whole year, pretty much because of my fibroids, because when I’m in pain, I’m in really bad pain.”

Difficulty staying asleep

Sleep issues

“But I would have to get up in the middle of the night and change my pad because I messed up my bed ... So, my sleep is interrupted, because I’m not sleeping through the whole night, you know, because I got to go change and—change sheets, change bed, you know, all that kind of stuff.”

What do the results of the study mean?

In this interview study:

- Women with heavy menstrual bleeding from uterine fibroids shared what it is like to live with their symptoms associated with uterine fibroids in their own words.
- Most women said that they had heavy menstrual bleeding, pelvic or groin pain, passing of blood clots, and anemia (or low hemoglobin in red blood cells). Pelvic or groin pain occurred on both menstrual and non-menstrual days.
- Women said their uterine fibroid symptoms had big effects on all parts of their lives by:
 - Stopping them from doing daily activities.
 - Causing them embarrassment and sadness.
 - Making them feel tired.

Women also had physical and financial problems because of their uterine fibroid symptoms.

- This study provided information on the serious impacts that heavy menstrual bleeding and other symptoms due to uterine fibroids have on the lives of women living with this condition.

Who sponsored this study?

This study was sponsored by Myovant Sciences GmbH (now Sumitomo Pharma Switzerland GmbH).

Aeschengraben 27, 4051, Basel, Switzerland, (650) 392 0222

This summary was funded by Pfizer and Sumitomo Pharma Switzerland GmbH.

Where can readers find more information about this study?

- The original article discussed in this summary is called, “The Burden of Uterine Fibroids from the Perspective of US Women Participating in Open-Ended Interviews” and was published in *Women’s Health Reports*
- The full citation for the original article is: Elke Hunsche, Viatcheslav Rakov, Kayla Scippa, Brooke Witherspoon, and Laura McKain: The Burden of Uterine Fibroids from the Perspective of US Women Participating in Open-Ended Interviews. *Women's Health Reports* (2022) 3:1, 286–296.
- You can read the full article for free at: <https://www.liebertpub.com/doi/full/10.1089/whr.2021.0086>

Acknowledgments

Sumitomo Pharma Switzerland GmbH and the authors thank all of the women who took part in these studies and their families, as well as the treating physicians, research nurses, study coordinators, and operations staff. Writing support for this summary was provided by Tricia Newell, PhD, of ICON (Blue Bell, PA) and was funded by Sumitomo Pharma Switzerland GmbH in partnership with Pfizer Inc.

Financial disclosure

Elke Hunsche and Viatcheslav Rakov are employed by Sumitomo Pharma Switzerland GmbH and are shareholders of the company. Laura McKain was an employee and a shareholder of Myovant Sciences at the time of writing. Brooke Witherspoon is employed by Lumanity Patient-Centered Outcomes, formerly Endpoint Outcomes, and was compensated by Myovant Sciences to conduct this research. Kayla Scippa was an employee of Endpoint Outcomes, now Lumanity Patient-Centered Outcomes, at the time this research was conducted. The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

Competing interests disclosure

The authors have no competing interests or relevant affiliations with any organization or entity with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.