



***Rethinking Perceptions of Normal Period Pain and Bleeding:  
A Guide to Understanding Uterine Fibroids and Treatment  
Options for Women in the U.S.***

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## INTRODUCTION

“I didn't call anybody because you know it was like this is normal,” said one woman who researchers asked about her fibroid symptoms, who was suffering from exceptionally heavy and long-lasting periods.<sup>1</sup> This is not uncommon among women with symptomatic fibroids — there is a general assumption of normalcy that goes with such issues. But those problems can be inconvenient and even debilitating, and women with fibroids do not need to simply live with them. Uterine fibroids are common, generally non-cancerous growths that most women experience at some point in their life. Not all fibroids result in symptoms, but many do, and they are common enough that women may think that what they are going through is simply normal. Knowing what is normal is tough — and health care providers and families need to help every woman understand what fibroids are and how, if experiencing fibroid symptoms, to get back to a real normal.

## PREVALENCE AND RISKS

We tend to think of health issues as atypical; however, in the case of fibroids, they are nearly ubiquitous. Over 80 percent of black women and close to 70 percent of white women are estimated to have uterine fibroids at some point before menopause.<sup>2</sup> While not all fibroids are symptomatic, 30-40 percent of fibroids cases are symptomatic.<sup>3</sup> Of course, the majority of fibroids are asymptomatic and get little clinical attention, often remaining undiagnosed.<sup>4</sup> Asymptomatic fibroids are generally harmless, with some researchers saying that fibroids should be left untreated unless they result in severe symptoms or health hazards.<sup>5</sup> However, fibroids that impinge on the uterine cavity can have adverse effects on fertility.<sup>6</sup>

All women with uteruses are at risk for fibroids. Several risk factors increase the chances of having fibroids, but many of the risk factors are not well understood. What is known, though, is

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<sup>1</sup> Ghant, Marissa, Katherine Sengoba, Robert Vogelzang, Angela Lawson, and Erica Marsh. 2016. "An Altered Perception of Normal: Understanding Causes for Treatment Delay in Women with Symptomatic Uterine Fibroids." *Journal of Women's Health* 846-852.

<sup>2</sup> Baird, DD, DB Dunson, MC Hill, D Cousins, and JM Schectman. 2003. "High Cumulative Incidence of Uterine Leiomyoma in Black and White Women: Ultrasound Evidence." *American Journal of Obstetrics and Gynecology*.

<sup>3</sup> Donnez, Jacques, and Marie-Madeleine Dolmans. 2016. "Uterine fibroid management: from the present to the future." *Human Reproduction Update*, July: 665-686.

<sup>4</sup> Zimmermann, Anne, David Bernuit, Christoph Gerlinger, Matthias Schaefer, and Katharina Geppert. 2012. "Prevalence, symptoms, and management of uterine fibroids: an international internet-based survey of 21,746 women." *BMC Women's Health*.

<sup>5</sup> Pritts, Elizabeth, and David Olive. 2012. "When Should Uterine Fibroids Be Treated?" *Current Obstetrics and Gynecology Reports*, 71-80.

<sup>6</sup> (Donnez and Dolmans 2016)

that fibroids appear to be hormone-responsive.<sup>7</sup> Fibroid risk appears to increase with age, but when women reach menopause and estrogen and progesterone levels decrease, fibroid risk decreases, and existing fibroids diminish.<sup>8</sup>

Other major risk factors include obesity and early menarche. As discussed above, fibroids appear to be hormone responsive, so earlier exposure to estrogen increases the likelihood of developing fibroids.<sup>9</sup> Pregnancy appears to protect against fibroids, though researchers do not understand why. Caffeine and alcohol intake, along with eating a lot of red meat, increase fibroid risk, while smoking decreases fibroid risk. The mechanisms for these risk factors are unknown.<sup>10</sup>

One of the most important risk factors for developing fibroids is race, with studies showing that African-American women are at higher risk of developing fibroids and of developing them earlier. Fibroid risk is 60 percent among African-American women by age 35, increasing to over 80 percent by age 50. Caucasian women, on the other hand, see a 40 percent rate of fibroids incidence by age 35, increasing to 70 percent by age 50.<sup>11</sup> These risk factors, combined with the very high incidence of fibroids among all women but particularly African-American women, underscore that women who display fibroid symptoms should seek evaluation and treatment. Having symptomatic fibroids is normal in that it is common, but it is not normal in that all women should be able to expect that the symptoms can be relieved.

### WHAT IS “NORMAL?”

Many of the symptoms associated with fibroids are shrugged off as “normal” or seen as just a fact of life. As a matter of prevalence, having fibroids is normal — but living with the symptoms does not need to be. Symptoms include heavy menstrual bleeding, pelvic pain, severe menstrual cramps, pressure and discomfort, urinary tract issues, and lessened fertility. The most common symptoms appear to be pelvic pain and heavy menstrual bleeding.<sup>12</sup> Such symptoms — particularly changing or worsening — may indicate that a visit to a doctor to confirm a diagnosis of fibroids is necessary. Diagnosis of fibroids can generally be confirmed by ultrasound; if inconclusive, magnetic resonance imaging (MRI) is considered the best secondary diagnosis option.<sup>13,14</sup> Other causes of such symptoms should be ruled out prior to pursuing treatment of fibroids.

There is significant variation even within normal periods, so women may believe that abnormal symptoms associated with fibroids are simply a matter of course. A typical menstrual cycle is 28

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<sup>7</sup> Walker, Cheryl Lyn, and Elizabeth Stewart. 2005. "Uterine Fibroids: The Elephant in the Room." *Science*, June 10: 1589-1592.

<sup>8</sup> Khan, Aamir, Manjeet Shehmar, and Janesh Gupta. 2014. "Uterine fibroids: current perspectives." *International Journal of Women's Health*, June: 95-114.

<sup>9</sup> (Khan, Shehmar and Gupta 2014)

<sup>10</sup> (Donnez and Dolmans 2016)

<sup>11</sup> (Donnez and Dolmans 2016)

<sup>12</sup> Lumsden, Mary Ann, Ibrahim Hamoodi, Janesh Gupta, and Martha Hickey. 2015. "Fibroids: diagnosis and management." *BMJ: British Medical Journal*, October 13.

<sup>13</sup> Lumsden et al (2015).

<sup>14</sup> (Khan, Shehmar and Gupta 2014)

days long, but a cycle is still “normal” if it is between 24 and 38 days.<sup>15</sup> Undergoing changes in the cycle can be indicative of fibroids, and women with fibroids can see irregular cycles or longer or more frequent periods.<sup>16</sup> A “normal” period results in the loss of 2-3 tablespoons of blood, and periods during which women bleed through more than one pad or tampon every one to two hours, passing clots larger than a quarter, or last more than eight days are considered heavy and may be indicative of fibroids. Feeling lightheaded or tired may also be indicative of anemia if accompanied by an abnormally heavy period. At the end of the day, changing periods or their unduly interfering with everyday life are a reason to investigate. Accepting fibroid symptoms as “normal” is unnecessary and there are a variety of treatment options to minimize the effects of fibroids. The perception of fibroids as “normal” leads to delayed treatment-seeking,<sup>17</sup> with the participants of one study of women with symptomatic fibroids waiting an average of 3.6 years to seek relief of fibroid systems.<sup>18</sup>

An interview-based study of sixty women confirmed these findings. Most of the women interviewed reported that they did not seek treatment for fibroids — and had delayed diagnoses — due to their belief that symptoms were normal. Women with fibroids have been found to not frequently know the parameters of what constitutes a “normal” period, resulting in their not having an impetus to seek care. Many women also had no prior knowledge of fibroids, and even many of those who did had no perception of themselves being at risk of fibroids. Many of the women interviewed said that they just dealt with the symptoms of fibroids, perceiving a lower severity than was truly reflected in their conditions, and avoided seeking help.<sup>19</sup>

The lack of knowledge about fibroids and “normal” periods and avoidance-based coping mechanisms exhibited by those interviewed shows a need for greater patient education by healthcare providers. Without knowing what is normal and what is avoidable, women will not seek treatment. The symptoms associated with fibroids can be debilitating, and women with fibroids need to be informed about the disease in order to get back to a “normal” asymptomatic state.

The Society of Interventional Radiologists Foundation developed the Uterine Fibroid Symptom Health-Related Quality of Life Questionnaire (UFS-QOL) to help women with fibroids and their health care providers assess the symptoms associated with fibroids.<sup>20</sup> Providers can consider using it or other evaluation tools when working with patients to determine a treatment.

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<sup>15</sup> U.S. Department of Health and Human Services. 2018. *Your Menstrual Cycle*. March. Accessed July 23, 2019. <https://www.womenshealth.gov/menstrual-cycle/your-menstrual-cycle>.

<sup>16</sup> (Zimmermann, et al. 2012)

<sup>17</sup> (Ghant, et al. 2016)

<sup>18</sup> Borah, B, W Nicholson, L Bradley, and E Stewart. 2013. "The impact of uterine leiomyomas: a national survey of affected women." *American Journal of Obstetrics and Gynecology* 319.e1-319.e20.

<sup>19</sup> (Ghant, et al. 2016)

<sup>20</sup> Society of Interventional Radiologists Foundation. n.d. *Uterine Fibroid Symptom Health-Related Quality of Life Questionnaire*. Accessed July 23, 2019.

## TREATMENT

Women with fibroids have choices to make. There is an expanding menu of treatment options, ranging from over-the-counter analgesics to mitigate symptoms to major surgical interventions. Each of these interventions varies in their efficacy, the circumstances under which they are appropriate, and the rate at which re-intervention is necessary.

There are some circumstances under which surgical or radiological treatment is necessary — debilitating bleeding caused by fibroids that is not respondent to medical interventions or the presence of sufficient fibroid mass as to cause urinary tract issues. Fibroids that cause a lack of fertility are cause for intervention in women who desire pregnancy, and all current medical interventions cause infertility during the course of treatment. Some medical therapies, as detailed below, are inappropriate for long-term use and should only be used as a preparation for surgery or as women enter menopause. The development of outpatient radiological procedures, such as the Acessa procedure, may make it easier for women to seek fibroid-eliminating treatment that does not result in long recoveries or infertility.<sup>21</sup>

Hysterectomy is the only current intervention that is 100 percent effective and requires no re-intervention to treat fibroids; however, it is a major surgery that is inappropriate for women who still want to bear children and results in a long recovery. Fibroids are the most common indication for hysterectomy, accounting for 26.9 percent of all hysterectomies performed in the U.S. in 2005. This is down from 31.4 percent just eight years previously, thanks in large part to the proliferation of alternative procedures.<sup>22</sup> One study found that women who seek a second opinion for treatment of symptomatic fibroids are less likely to undergo a hysterectomy, instead opting for less drastic procedures including medical intervention, myomectomy, or radiological options.<sup>23</sup> Myomectomy, or the surgical removal of fibroids from the uterus, is fertility-preserving and comes with a faster recovery time. However, recovery times can still be significant, particularly when myomectomy is performed in an open surgery, but range significantly.<sup>24</sup>

Medical interventions are generally either used only for short-term therapies or their efficacy in the presence of fibroids is unknown. They are often used in preparation for surgery or if a patient is nearing or entering menopause for short-term symptom relief. Exceptions to this, as detailed below, are oral contraceptives and levonorgestrel intra-uterine devices, though there is little evidence of their effect in the presence of fibroids.

A patient-centered approach to fibroid management is vital. Appropriate treatment is dependent on an individual woman's circumstances and preferences. Desire to bear children, side effects, and balancing intervention intensity with patients' needs are all vitally important factors when determining treatment, and new advances are promising in their ability to reduce trade-offs.

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<sup>21</sup> (Pritts and Olive 2012)

<sup>22</sup> Wise, Lauren, and Shannon Laughlin-Tommaso. 2016. "Epidemiology of Uterine Fibroids – From Menarche to Menopause." *Clinical Obstetrics and Gynecology*, March: 2-24.

<sup>23</sup> Mayor, Susan. 2014. "Second opinion reduces hysterectomies for uterine fibroids, study shows." *BMJ: British Medical Journal*, April 15.

<sup>24</sup> (Khan, Shehmar and Gupta 2014)

Medical interventions can be considered particularly when heavy menstrual bleeding is the only symptom, otherwise, surgical or radiological interventions are preferred.

**Table 1: Interventions**<sup>25,26,27,28,29</sup>

Intervention	Description
<b>Medical Interventions</b>	
Tranexamic Acid	Can decrease menstrual bleeding by up to 50 percent. However, evidence in presence of fibroids is lacking.
Oral Contraceptives	Can decrease menstrual bleeding; however, early use (before age 17) is associated with greater incidence of fibroids.
Levonorgestrel	Levonorgestrel, delivered as an intra-uterine device (IUD), reduces menstrual blood loss (up to 94 percent) and can be considered as an alternative to surgery if heavy menstrual bleeding is the primary symptom. Evidence in the presence of fibroids is limited.
GnRH Analogs	Induce fibroid shrinkage through action on the pituitary gland. Not appropriate for long-term use.
Selective Estrogen Receptor Modulators (SERMs)	Blocks certain estrogen activity, which is linked to fibroid growth and proliferation. Can reduce bleeding and pressure symptoms. Generally inappropriate for long-term use.
Selective Progesterone Receptor Modulators (SPRMs)	Blocks certain progesterone activity on target tissues. Progesterone appears to be associated with the proliferation of fibroids. Clinical trials have established that SPRMs may be appropriate for treatment of uterine fibroids, associating their use with reduced pain, bleeding, fibroid size, and quality-of-life improvements. Long-term use can result in endometrial issues.
<b>Surgical Interventions</b>	
Myomectomy	Targeted intervention to remove individual fibroids. Studies show that myomectomy patients have around a 45 percent pregnancy rate post-operation. Can be performed laparoscopically, hysteroscopically, or in a traditional abdominal surgery. Has a quicker recovery period than hysterectomy. Myomectomy may have an up to 59 percent post-operative recurrence rate.
Hysterectomy	Removal of the uterus. Precludes fertility. Multi-month recovery period, but zero percent fibroid recurrence rate.
<b>Radiological Interventions</b>	

<sup>25</sup> (Fischer, et al. 2015)

<sup>26</sup> (Khan, Shehmar and Gupta 2014)

<sup>27</sup> (Donnez and Dolmans 2016)

<sup>28</sup> (Lumsden, et al. 2015)

<sup>29</sup> Lee, Bruce, and Steve Yu. 2016. "Radiofrequency Ablation of Uterine Fibroids: a Review." *Current Obstetrics and Gynecology Reports* 318-324.

**Table 1: Interventions**<sup>25,26,27,28,29</sup>

Intervention	Description
Uterine Artery Embolization (UAE)	Image-guided procedure to inject embolic agents into some uterine arteries to cut off blood flow to fibroids, causing them to die and shrink. Full patient recovery takes 8-14 days. One study found that the pregnancy rate for women who underwent UAE is 50 percent. However, there is a high re-intervention rate associated with UAE.
MRI-guided Focused Ultrasound Surgery (MRgFUS)	Uses focused ultrasound to converge on a target and cause a temperature rise that induces cell death in the fibroid target. Relatively few patients are eligible for this treatment as fibroids must have a location that is accessible to the focused ultrasound. A study showed that pregnancy outcomes post-MRgFUS are comparable to women without fibroids.
Radiofrequency Thermal Ablation	Radiofrequency thermal ablation, such as that made possible by the VizAblate and Acessa devices, is a procedure that uses real-time imaging to target individual fibroids and apply heat to them and cause cell death in just the fibroid. Such procedures are conducted on an outpatient basis and have very quick recovery times compared to surgical options or UAE. Re-intervention rates for the Acessa procedure has been shown to be low (11 percent).

Women with symptomatic fibroids — which number many — often do not even know that there is something wrong or fixable. Many say they just “suck it up” in regard to the symptoms or think that what they are experiencing is perfectly normal.<sup>30</sup> Increased awareness of fibroids, spearheaded by patients and health care providers, can lead women with symptomatic fibroids to seek treatment. Knowing that fibroid symptoms are not “normal” and that treatments are available and improving can help free women from burdens associated with fibroids. Advances in medical and radiological interventions in particular can help manage symptoms or remove fibroids with little other impact and recovery time. Ensuring that women are able to access these treatments will help them to live full, fulfilling lives free of fibroids.

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<sup>30</sup> (Ghant, et al. 2016)