



Report: The Financial Impact of Uterine Fibroids

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Introduction

Uterine fibroids are the most common gynecological condition among women,¹ with lifetime prevalence exceeding 80 percent among Black women and approaching 70 percent among White women.² Much less is known regarding the impact of fibroids in the Hispanic, Asian, and other racial and ethnic communities.³ We know that fibroid costs to the U.S. economy amount to nearly \$34 billion annually, including up to \$17 billion in lost productivity,⁴ but these numbers only tell part of the story.



Care About Fibroids' first white paper published in 2019 discussed the high rates of absenteeism, lost productivity, and other hidden costs of uterine fibroids.⁵ The paper found that women take on a \$4,624 financial burden in the first year of diagnosis.⁶ A subsequent discussion of fibroids' cost burden caught the attention of lawmakers, policy experts, patients, and advocates during the organization's 2019 Capitol Hill policy briefing and helped drive introduction of the Uterine Fibroids Research and Education Act of 2020. This report aims to provide a deeper analysis and explanation of the specific factors directly associated with the financial impact on women with fibroids.

For additional insight into the financial burden of fibroids among women in the U.S., we will refer to data from a recent survey executed by CARE About Fibroids and its partner, Responsum Health. Responsum Health questioned 50 women through their mobile application and 50 women through the online survey platform, Pollfish. The Responsum polling audience was a community of engaged uterine fibroids patients, while the Pollfish audience was random. The Responsum survey demographics included a majority Black patient group and the Pollfish demographics were majority White. Utilizing these two collection methods, polling data created a sample that attempts to depict the diverse population of women with fibroids. Responsum found insignificant differences in responses between different racial and ethnic groups.

¹ Please note that non-binary individuals can also experience uterine fibroids.

² Stewart EA. Uterine Fibroids. *New England Journal of Medicine*. April 23, 2015. Accessed January 11, 2021. Available at: <https://www.nejm.org/doi/full/10.1056/NEJMcp1411029>

³ Mostafavi, B. (2020, August 12). Understanding Racial Disparities for Women with Uterine Fibroids. *University of Michigan Health Lab*. <https://labblog.uofmhealth.org/rounds/understanding-racial-disparities-for-women-uterine-fibroids>.

⁴ Cardozo, E. R., Clark, A. D., Banks, N. K., Henne, M. B., Stegmann, B. J., & Segars, J. H. (2012). The estimated annual cost of uterine leiomyomata in the United States. *American journal of obstetrics and gynecology*, 206(3), 211-e1.

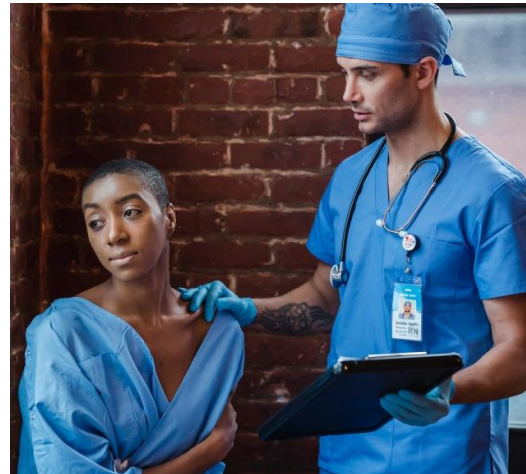
⁵ Care About Fibroids. (2019). *Uterine Fibroids: A Report on the condition and its impact on women in the U.S.* [White paper]. CAREaboutFibroids.

http://www.careaboutfibroids.org/uploads/8/4/2/1/8421729/a_report_on_the_condition_and_its_impact_on_women_in_the_u.s..pdf

⁶ Care About Fibroids, 2019.

Surgical Costs

The most common solution for fibroids today is a hysterectomy, eliminating a woman’s ability to have children. Even with insurance, this procedure can cost patients nearly \$12,000 in out of pocket costs and can present a considerable barrier to patient care.⁷ According to the recent survey with Responsum Health, 61 percent of fibroid patients have delayed or avoided treatment due to financial concerns.⁸ A patient will spend more than four times more on medical bills than women without fibroids in their first year after diagnosis, amounting to almost \$14,000.⁹ After the hurdles of that first year, patients will continue to spend thousands of dollars more than their non-fibroids peers annually.¹⁰ Black women overwhelmingly express insurance coverage concerns. Indeed, 75 percent of Black women, compared to 15 percent of White women, report that they have inadequate insurance coverage.¹¹ Coverage inadequacy often forces women to delay treatment, exacerbating their excruciating symptoms.¹²



“...but I never took care of it because I didn’t have insurance...I would like to have them taken out of me now, but of course it is not happening because I don’t have insurance. I hate the heavy periods, I hate them with a passion and it’s not just the periods—it is the cramps. The cramps are so intense right now it is not even funny... it is hard for me to move around, get out of my car.”¹³

To avoid a hysterectomy and preserve their uterus, some women will undergo uterine artery embolization (UAE). While this procedure is seemingly more cost-effective,¹⁴ up to 30 percent of women who undergo UAE need to have the procedure again within one or two years, or they may still need a hysterectomy.¹⁵ Women often pay to undergo UAE believing that their struggle with fibroids is over, only to be disappointed and forego future treatment. Patients are forced to make difficult decisions to prioritize health or financial security, often at the expense of

⁷ Cardozo, et al., 2012.

⁸ See Responsum Survey at Appendix I

⁹ Fuldeore, M., Yang, H., Soliman, A. M., & Winkel, C. (2015). Healthcare utilization and costs among women diagnosed with uterine fibroids: a longitudinal evaluation for 5 years pre- and post-diagnosis. *Current Medical Research and Opinion*, 31(9), 1719-1731.

¹⁰ Fuldeore, et al., 2015

¹¹ Sengoba, K. S., Ghant, M. S., Okeigwe, I., Mendoza, G., & Marsh, E. E. (2017). Racial/ethnic differences in women’s experiences with symptomatic uterine fibroids: a qualitative assessment. *Journal of racial and ethnic health disparities*, 4(2), 178-183.

¹² Sengoba, et al., 2017.

¹³ Sengoba, et al., 2017.

¹⁴ Beinfeld, M. T., Bosch, J. L., Isaacson, K. B., & Gazelle, G. S. (2004). Cost-effectiveness of uterine artery embolization and hysterectomy for uterine fibroids. *Radiology*, 230(1), 207–213. <https://doi.org/10.1148/radiol.2301021482>

¹⁵ UCLA Obstetrics and Gynecology. (n.d.). *Uterine Artery Embolization*. UCLA Health.

<https://www.uclahealth.org/obgyn/uterine-artery-embolization#:~:text=Uterine%20artery%20embolization%20usually%20works,5%20years%20after%20the%20procedure>

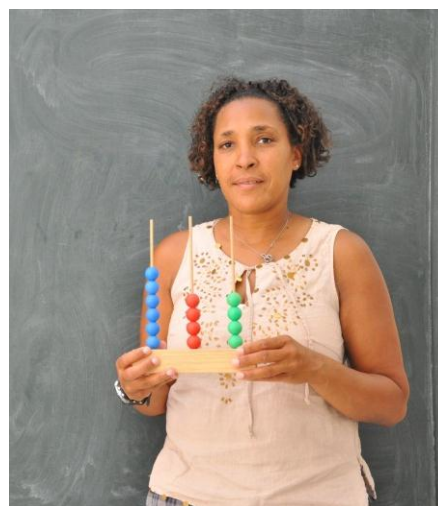
mental health and important relationships. In one recent study, half of the women expressed feeling completely helpless and alone when it came to managing their fibroids.¹⁶

“One of my aunts was like, ‘I don't know why you are looking for alternative medicine, you just need to have a hysterectomy and get it over with’ I have an aunt right now who is not speaking to me because I won't have a hysterectomy. She feels like I am causing the family stress by not just having it.”¹⁷

Career Sacrifices

Looking back on their careers, 75 percent of women said that fibroids have hindered their professional goals. In addition to lowering career prospects, 51 percent of women reported struggling to maintain a reliable, consistent source of income while dealing with their fibroids.¹⁸

For those who choose it, surgery is not a simple solution. Even after a procedure, fibroids patients can lose anywhere from \$14,000 to \$30,000 per year due to absenteeism from work.¹⁹ Studies show that women with fibroids experience performance limitations at their jobs in which pain from their fibroids interferes with their time management and ability to manage interpersonal tasks at nearly double the rate of other employees.²⁰ Women of color often grapple with even larger impairments in the workplace due to their fibroids.²¹



“I have hesitated to change careers or get more training because I am worried about how much time, preparation, and recovery for surgery will require.”²²

These workplace limitations can force women to choose between their health and career. According to McLeod Health, a typical woman with symptomatic fibroids will wait more than three years before seeking treatment, prolonging the stress of the chronic pain while maintaining an income. At the same time, 62 percent of women reported forgoing treatment altogether, or delaying treatment, due to career concerns.²³

Some patients seeking to find insurance coverage for fibroids procedures also have to consider if their employer's health insurance will cover treatment, compounding women's concerns of wage and hiring discrimination.

¹⁶ Ghant, M. S., Sengoba, K. S., Recht, H., Cameron, K. A., Lawson, A. K., & Marsh, E. E. (2015). Beyond the physical: a qualitative assessment of the burden of symptomatic uterine fibroids on women's emotional and psychosocial health. *Journal of psychosomatic research*, 78(5), 499–503.

¹⁷ Ghant, et al., 2015.

¹⁸ See Responsum Survey at Appendix I

¹⁹ Cardozo, et al., 2012.

²⁰ Lerner, et al., 2008.

²¹ Lerner, et al., 2008.

²² See Responsum Survey at Appendix I

²³ See Responsum Survey at Appendix I

The Costs of Fibroids-Related Pregnancy Complications

When factoring in care during pregnancy and post-partum, the cost of childbirth in the U.S. is about \$30,000.²⁴ Women with fibroids experience increased costs while trying to conceive, during childbirth, and post-partum. Without surgically removing fibroids, conception may be difficult, and the cost of fertility treatments can be exorbitant. One patient explained that she experienced difficulties conceiving due to her fibroids, had to undergo multiple surgeries to remove her fibroids, and now has to undergo expensive in-vitro fertilization (IVF) costs.²⁵ Physicians often consider surgical procedures as a prerequisite to ease possible complications from fibroids, however, more surgical procedures often lead to reduced chances of becoming pregnant.

“I still feel like there's less of me because of this ... all my friends are pregnant, all my friends have babies, we all started trying at the same time and I'm the only one that didn't get pregnant ... it's because of the fibroids.”²⁶



Throughout pregnancy, a higher risk of “spontaneous miscarriage, preterm labor, placenta abruption, malpresentation, labor dystocia, cesarean delivery, and postpartum hemorrhage”²⁷ can require additional physician monitoring, which incur more costs. This additional diligence is intended to prevent birthing complications, but fibroids can still cause harm to the fetus. Cesarean delivery is the most common complication due to fibroids, which costs between \$13,745-\$20,298 and \$4,000 for out-of-pocket costs.²⁸ Preterm deliveries, the second most common complication due to fibroids, cost about \$52,000²⁹

²⁴ Borden, T. & Hoffower, H. (9 December 2019). *Business Insider*. How much it costs to have a baby in every state, whether you have health insurance or don't <https://www.businessinsider.com/how-much-does-it-cost-to-have-a-baby-20184#:~:text=The%20cost%20of%20having%20a%20baby%20isn't%20cheap%20%E2%80%94%20in,provided%20before%20and%20after%20pregnancy>

²⁵ See Responsum Survey at Appendix I

²⁶ Ghant, et al., 2015.

²⁷ Lee, H. J., Norwitz, E. R., & Shaw, J. (2010). Contemporary management of fibroids in pregnancy. *Reviews in obstetrics & gynecology*, 3(1), 20–27.

²⁸ Corry, M. P., Delbanco, S. F., & Miller, H. D. (2013). The cost of having a baby in the United States. *Truven Health Analytics, Greenwood Village, CO, USA*.

²⁹ Cardozo, et al., 2012.

Economics Associated with Short- and Long-Term Use of Feminine Hygiene Products

Complications from fibroids can turn even the necessary cost of feminine hygiene products into a cumbersome financial burden for women of limited means. In a study of women with fibroids, a substantial number of participants shared their struggles to manage these costs. All of these participants were women of color.³⁰ Overall, 66 percent of women reported needing to purchase additional feminine hygiene products, and one fibroids patient said that she “had to stay at home or go out with numerous supplies to ensure I would not bleed out [through my clothing].”³¹ Women with uterine fibroids experienced 23 percent heavier bleeding, 22 percent experienced longer periods, and 20 percent have more bleeding in between periods compared to women without uterine fibroids.³²



“Buying Depends, which are very expensive, and also tampons and pads, more than usual. I probably spend \$100 [a month] on that stuff they’re not cheap at all.”³³

The expense of regularly purchasing additional sanitary products can be compounded by the perceived need to buy organic, high-quality products. Some women have found that irritants from chemicals in sanitary products can aggravate their fibroids.³⁴ Increased sensitivity due to non-organic products is also a prominent concern in the development of a uterine fibroids patient’s diet.

Special Dietary Needs Can Lead to Additional Financial Burden

More than 40 percent of women with fibroids from the Responsum survey reported maintaining a specialized diet to ease their symptoms.³⁵ While food is a primary expense for most American families, some women with fibroids may spend more due to dietary needs. Epidemiological evidence indicates that dietary components can have an effect on hormone-related conditions, such as uterine fibroids.³⁶ Factors including fruit and vegetable intake, vitamin D intake, and pollutants in non-organic

³⁰ Sengoba, et al., 2017.

³¹ See Responsum Survey at Appendix I

³² Zimmermann, A., Bernuit, D., Gerlinger, C. *et al.* Prevalence, symptoms and management of uterine fibroids: an international internet-based survey of 21,746 women. *BMC Women's Health* 12, 6 (2012).

³³ Sengoba, et al., 2017

³⁴ Rorise (personal communication, August 25, 2020) discussed her journey with fibroids in an interview. Her last has been slightly modified at the patient’s request.

³⁵ See Responsum Survey at Appendix

³⁶ Tinelli, A., Vinciguerra, M., Malvasi, A., Andjić, M., Babović, I., & Sparić, R. (2021). Uterine Fibroids and Diet. *International journal of environmental research and public health*, 18(3), 1066. <https://doi.org/10.3390/ijerph18031066>

food can all impact fibroid growth and inflammation.³⁷

One patient described her trial-and-error experience with her diet. She explained that an organic diet, while helpful for her symptoms, was incredibly difficult to manage. While this diet eliminated potentially harmful pesticides and hormones, it was more costly. When she decided to attend night school and get a degree to provide for her family, maintaining this rigorous diet was incredibly difficult. As her diet began to slip, she felt her education shift further out of reach while her fibroids symptoms became overwhelming.³⁸

Conclusion



In the recent survey conducted by Responsum Health, 57 percent of women reported needing financial assistance from friends and family to manage their fibroids-related costs, with more than 50 percent of those women not having the privilege of a satisfactory financial support network.³⁹ These high rates of financial need are still not well studied nor understood, but the ripple effect of living with uterine fibroids – as explored in this report – expands our understanding of the costs of this condition. For many women, spending \$11,500 for a hysterectomy, \$14,000 in costs during the first year of diagnosis, losing another \$14,000 in absenteeism, anywhere from \$13,000 to \$57,000 due to pregnancy complications, \$100 per month on sanitary products, and higher food costs can combine to create a crippling financial circumstance. For women of color experiencing disparities in the health care, these costs can be even more detrimental to their well-being and quality of life.

Women with fibroids already live with the burden of managing their chronic symptoms day to day, but the concomitant financial challenges are substantial, omnipresent, and often out of their control. Even beyond these documented expenses, the true costs of stifled careers, inadequate insurance coverage, disparate impacts on women of color, and other factors require further research. In learning more about fibroids and its impact on millions of women in America, we can expose the true impacts of this chronic condition and work to address and create a heightened sense of urgency around its painful physical, mental, and financial burdens.

³⁷ Tinelli, et al., 2001

³⁸ Rorise, personal communication, August 25, 2020.

³⁹ See Responsum Survey at Appendix I

Appendix I

Below is a table of the results from the Responsum Health survey of women with uterine fibroids. 49-50 women filled out the survey on the Responsum Health app, and 100 women responded to the survey through Pollfish. The Pollfish respondent demographics were 82% white, while 62% of respondents through the Responsum app identified as Black/ African American. To make the survey more equitable and best reflect the uterine fibroid population, the survey data below utilizes 100% of the Responsum results, and 50% of the Pollfish results.

Question & Source	Reponses					
Are you currently dealing with fibroids?	yes	no				
<i>Responsum:</i>	42	7				
<i>Pollfish:</i>	37	13				
<i>total (out of 99):</i>	79	20				
%:	79.7979798	20.2020202				
Age	18-24	25-34	35-44	45-54	> 54	
<i>Responsum:</i>	0	13	25	10	0	
<i>Pollfish:</i>	1.5	16.5	22	4.5	5.5	
<i>total (out of 98):</i>	1.5	29.5	47	14.5	5.5	
%:	1.530612245	30.10204082	47.95918367	14.79591837	5.612244898	
Race	White/ Caucasian	Black/ African American	Hispanic/ Latino	Asian/ Pacific Islander	Native American	Other
<i>Responsum:</i>	12	29	2	3	1	3
<i>Pollfish:</i>	41	3	6	4	2.5	1.5
<i>total (out of 98):</i>	53	32	8	7	3.5	4.5
%:	54.08163265	32.65306122	8.163265306	7.142857143	3.571428571	4.591836735
Do you understand what other treatment options are available for fibroids besides surgery?	yes	no				
<i>Responsum:</i>	31	18				
<i>Pollfish:</i>	29.5	20.5				
<i>total (out of 99):</i>	60.5	38.5				
%:	61.11111111	38.88888889				
Have you ever chosen to avoid or delay treatment	yes	no				

for your fibroids at any point due to financial reasons?						
<i>Responsum:</i>	27	22				
<i>Pollfish:</i>	29	21				
<i>total (out of 99):</i>	56	43				
<i>%:</i>	56.56565657	43.43434343				
What led you to delay or forego treatment? (Please check all that apply.) out of the 56.5% who chose to delay treatment	Treatment was too expensive.	I would have to take too much time off from work.	I didn't have anyone to care for me during recovery.	other		
<i>Responsum:</i>	19	19	9	8		
<i>Pollfish:</i>	27.5	28	16	5.5		
<i>total (out of 76):</i>	46.5	47	25	13.5		
<i>%:</i>	61.18421053	61.84210526	32.89473684	17.76315789		
Have you needed to rely on family or friends to help to cover any costs associated with your fibroids? (This can include medical costs, caretaking, food assistance, housing, etc.)	Yes, others have helped me cover some costs.	No, I did not need financial assistance from anyone.	I needed financial assistance, but I did not receive any.			
<i>Responsum:</i>	6	28	14			
<i>Pollfish:</i>	21	14	15			
<i>total (out of 98):</i>	27	42	29			
<i>%:</i>	27.55102041	42.85714286	29.59183673			
Looking back on your career goals pre-diagnosis, do you feel that your	Yes	Somewhat	No			

fibroids have hindered your career trajectory?						
<i>Responsum:</i>	15	18	15			
<i>Pollfish:</i>	17.5	22	10.5			
<i>total (out of 98):</i>	32.5	40	25.5			
%:	33.16326531	40.81632653	26.02040816			
Have (or did) your fibroids made it more difficult for you to maintain a consistent, reliable income?	Yes	Somewhat	No			
<i>Responsum:</i>	10	11	27			
<i>Pollfish:</i>	18	20.5	11.5			
<i>total (out of 98):</i>	28	31.5	38.5			
%:	28.57142857	32.14285714	39.28571429			
Due to fibroids... (Please check all that apply.)	I have experienced increased costs due to mental health treatment	My spouse/family has had to take on greater financial responsibility.	I have had to pay for more feminine hygiene (menstrual) products than usual	I have been unable to accumulate as much in personal savings.	I cannot provide for my children as much as I would like.	I have difficulty paying non-medical bills.
<i>Responsum:</i>	6	10	42	15	3	9
<i>Pollfish:</i>	19.5	23.5	28.5	13.5	10.5	13
<i>total (out of 98):</i>	25.5	33.5	70.5	28.5	13.5	22
%:	26.02040816	34.18367347	71.93877551	29.08163265	13.7755102	22.44897959
Due to fibroids... (Please check all that apply.) Con't	I have to maintain an expensive diet to ease my symptoms.	My quality of life was lowered (before myomectomy). I had to stay at home or go out with numerous supplies to ensure I would not bleed out.	I have not been able to conceive and have had to undergo multiple surgeries to remove and now have to undergo IVF treatment	I cannot work due to the size of my fibroids since I have been unable to afford treatment.	other	
<i>Responsum:</i>	26	1	1	1	2	
<i>Pollfish:</i>	16.5	0	0	0	3	
<i>total (out of 98):</i>	42.5	1	1	1	5	
%:	43.36734694	1.020408163	1.020408163	1.020408163	5.102040816	

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For more information about this report, or uterine fibroids more generally, please contact Executive Director Jenny Rosenberg at jtr@careaboutfibroids.org.