



A REPORT ON THE SEXUAL AND EMOTIONAL IMPACT OF UTERINE FIBROIDS

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“There’s less of me because of this.”¹

Introduction

Uterine fibroids affect a wide cross-section of the population and can negatively impact the quality of life of women affected. While these benign tumors are common, not all women with uterine fibroids have symptomatic fibroids. Studies show that one in four women who have uterine fibroids have symptoms that require treatment. Symptomatic fibroids often bring about a change in the emotional and psychosocial well being of an individual. In this paper, the burden that symptomatic fibroids has on a woman’s emotional, mental, and psychological well-being affects her sexual health specifically, and her quality of life more generally.

Emotional, Mental, and Psychological Impact

While the physical impacts of uterine fibroids have been well-documented and researched, little has been done to explore a woman’s emotional, mental, and psychological impact. We need to understand how the physical outcomes of uterine fibroids affect a woman emotionally, mentally, and psychologically. The chronic nature of the symptoms can have a severe impact a woman’s day-to-day activities which makes it challenging to maintain her emotional well-being.² And while the emotional responses of women may vary, a common emotional response is the concern of self-image and worth.³

The physical outcomes of uterine fibroids affect women emotionally, mentally, and psychologically.

In a 2014 study conducted at the Northwestern University Feinberg School of Medicine⁴, 48 women with symptomatic uterine fibroids who were recruited from community-based organizations were asked to describe the psychological distress that uterine fibroids had on their lives, one participant said:

“I became a little worried because I am like - something is wrong with me and I don’t understand it. I actually thought at one point...am I dying. God, am I dying?”

In this study, 68 percent of women expressed that they felt concerned, worried, and scared before receiving their diagnosis. This was primarily because they did not understand what was happening to their bodies. And while the individuals in this study expressed relief that it

¹ Ghant, M. S., A. K. Lawson, K. S. Sengoba, H. Recht, G. Mendoza, J. M. McGuire, and E. E. Marsh. "Beyond the physical: a qualitative assessment of the emotional burden of symptomatic uterine fibroids on women’s mental health." *Fertility and Sterility* 102, no. 3 (2014): e248.

² Al-Hendy, A., Myers, E. R., & Stewart, E. (2017). Uterine Fibroids: Burden and Unmet Medical Need. *Seminars in reproductive medicine*, 35(6), 473–480. doi:10.1055/s-0037-1607264

³ Levy G, Hill MJ, Beall S, Zarek Sm, Segars JH, Catherino WH. Leiomyoma: genetics, assisted production, pregnancy, and therapeutic advances. *J Assist Reprod Genet* 2012; 29 (08): 703-712

⁴ (Ghant, et al. 2016)

was not something that they considered to be worse, such as cancer, they still expressed fear of what was occurring to their bodies. Some women discussed, at length, how their fibroid-related symptoms caused them to feel sad and depressed:

“All of this has caused me to be depressed and it makes me feel inadequate... this is just wearing me down.”⁵

While some women communicated feelings of sadness and depression, others expressed a notable amount of frustration, anger, and hate toward their fibroids. Their emotions were primarily focused on how the tumors affected their ability to become pregnant, and the fibroids’ impact on their ability to have a productive social life.

Many of the study’s subjects stated that because of the possibility of heavy bleeding-related accidents, they were forced too often to cancel scheduled plans or to avoid making plans entirely.

Women in the Northwestern study also expressed a general sense of helplessness regarding their ability to manage their fibroids. They described how their symptoms left them feeling “out of control” and unable to improve their quality of life.⁶ Furthermore, they expressed an inability to complete everyday tasks, a sentiment that they did not “feel like” themselves, and a hopelessness regarding treatment options as they recognized there were no other options outside of surgery.⁷ Although women’s psychological distress caused by uterine fibroids has not previously been given much attention, it is a major component of symptomatic fibroids that must be addressed when trying to improve her quality of life.

Sexual Function

Concerns surrounding body image and sexuality are found to be among the top concerns of women experiencing symptomatic fibroids. In the national survey reported by Borah et al., 37 percent of women with uterine fibroids reported feeling conscious about the size and appearance of their stomachs and 20 percent believed that the fibroids impacted relationships with their partners all or most of the time.⁸ Moreover, these women were bothered by the appearance of being pregnant or overweight because of their tumors, and led to them to feeling less attractive. Patients also stated that their fibroids made them feel less attractive because they could not wear clothing they wanted to wear, or simply because they knew their fibroids were present. As a result of this change in their own self-perception, the women had greater difficulty becoming intimate with their partners. Additionally, a number of them believed their fibroids caused them to feel “less than a woman” because the fibroids significantly altered their bodies.⁹

⁵ (Ghant, et al. 2016)

⁶ (Ghant, et al. 2016)

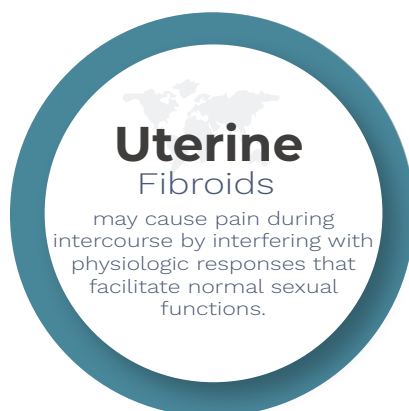
⁷ Nicholls C, Glover L., Pistrang N. The illness experiences of women with fibroids: an exploratory qualitative study. J Psychosom Obstet Gynecol 2004;25: 295-304

⁸ Borah BJ, Nicholson WK, Bradley L, Stewart EA. The impact of uterine leiomyomas: a national survey of affected women. Am J Obstet Gynecol 2013; 209 319 e1-e20.

⁹ (Ghant, et al. 2016)

“I didn’t care for my partner to see me naked because I felt my shape would look so bad. It was embarrassing.”¹⁰

In addition to the effect on their body image and self-esteem, uterine fibroids have the potential to cause pain during intercourse by interfering with physiologic responses that facilitate normal sexual functions. Orgasm, which is characterized by contractions of the uterus, cervix, and vaginal musculature, can be altered by the presence of fibroid(s) or the fibroid(s) may cause tenting and cervical elevation during intercourse. Barriers exist when addressing issues of sexual dysfunction in women living with uterine fibroids. Individuals with symptomatic fibroids are often reluctant to discuss this issue as it involves having to confront feelings of inadequacy and rejection.¹¹



While statistics show that treatments for fibroids are generally successful in controlling many fibroid symptoms and sequelae, sexual function following surgical treatments for fibroids can be jeopardized. Of note, there is a controversy in the medical literature regarding quality of life and sexual function following surgical treatment for fibroids.¹² A number of studies related to hysterectomy and female sexual functioning have led researchers to conclude that the disruption of the automatic nerve supply leads to sexual function disturbances. Specifically, the disruption of the sympathetic nerve supply can lead to impaired lubrication, altered sensation of the female internal genital organs, and damage to the parasympathetic nerve supply.¹³ In addition, some research has suggested the removal of the cervix can eliminate internal orgasm.¹⁴ Hysterectomies have been shown to affect not only internal

¹⁰ (Ghant, et al. 2016)

¹¹ H.M. Hasson, “Cervical removal at hysterectomy for benign disease: risks and benefits,” *Journal of Reproductive Medicine for the Obstetrician and Gynecologist*, vol. 38, no.10, pp. 781-790, 1993.

¹² D.Ertunc, R. Unzun, E.C. Tok, A.Doruk, and S. Dilek, “The effect of myoma uteri and myomectomy on sexual function,” *Journal of Sexual Medicine*, vol. 6, no.4, pp. 1934 – 1941, 1999.

¹³ S. A. Butler-Manuel, L.D.K. Buttery, R.P.A’Hern, J.M. Polak, and D. P J. Barton, “Pelvic nerve plexus trauma at radical and simple hysterectomy: a quantitative study of nerves types in the uterine supporting ligaments,” *Journal of the Society Investigation*, vol.9, no. 1, pp. 47- 56, 2002.

¹⁴ (H.M.Hasson, et al.1993)

orgasms, but external orgasms as well. For instance, external orgasm is reliant on the pudendal nerve which supplies sensation to the labia and clitoris. Both can be affected by hysterectomy and contribute to sexual dysfunction.¹⁵

Conclusion

Symptomatic uterine fibroids greatly affect the daily living and quality of life of women who have them. While the physical outcomes of uterine fibroids have been well-documented, little investment has been made into research around their impact on a woman's emotional, mental, and psychological well-being. Because uterine fibroids impact a wide cross-section of the female population, we must understand implications of the physical outcomes of symptomatic uterine fibroids. Negative outcomes include, but are not limited to, concerns around self-image, inadequacy, helplessness, loss of control, and severe impact on the self-esteem of a woman. In turn, these concerns and emotions, may have an effect on the sexual function and vitality of a woman's sexual health. For example, the physical appearance of having uterine fibroids can sometimes be confused with appearing to be pregnant or overweight leading to a woman's decreased sense of comfort in her own skin. To better serve and support individuals living with symptomatic uterine fibroids, providers, physicians, community advocates, and activists need to understand the overreaching impact that uterine fibroids have on the women who have to confront their existence every day.



¹⁵ E. J. J. Beard, "The sexuality of spinal cord injured women: physiology and pathophysiology. A review." Paraplegia, vol. 27, no. 2, pp.99-112, 1989.