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Fibroids: “New” Options, Not Enough Answers

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The Women's Health Activist Newsletter

By Nekose Wills

For the past year and a half, I have overseen the Network’s health information service, the Women’s Health Voice. During this time I have become quite familiar with the subject of uterine fibroids, benign lumps of muscle and tissue that grow in and around the uterus. A quarter of the health requests we receive deal with fibroids and/or hysterectomy. Since the traditional way to treat fibroids is to have a hysterectomy (surgery to remove the uterus), the two have unfortunately become intertwined. Between 2000-2004, fibroids were one of the three conditions most often associated with hysterectomy. It is no surprise that women with fibroids often contact us to learn about alternatives to hysterectomy.¹ Since fibroids mainly affect women in their 30s and 40s, treating fibroids while preserving both the uterus and fertility is important to many of the women who call the Network.²

The U.S. history of hysterectomy highlights why so many women seek information from the Network. Between 1965-1984, hysterectomy was one of the most frequently performed major surgical procedures. The number of hysterectomies peaked in 1975 at 725,000 annually.³ In 2000, approximately 633,000 women had a hysterectomy, 90 percent of which were performed before the woman began menopause.⁴ Hysterectomy is the second most frequently performed surgical procedure on U.S. women, after Cesarean sections. By age 65, 37% of all U.S. women will have had a hysterectomy.⁵ Despite the declines, the U.S. still has one of the highest hysterectomy rates in the world. The Centers for Disease Control and Prevention (CDC) estimates that 600,000 hysterectomies were performed in 2004.⁶ In comparison, the United Kingdom’s (U.K.) National Health Services estimates that it performs 40,000 hysterectomies annually, which is considered a high rate.⁷ The overall U.S rate is 5.1 hysterectomies per 1,000 women, compared to less than 3 hysterectomies per 1,000 women in the U.K.

Ironically, hysterectomy is considered an elective surgery and is usually performed to address abnormal uterine bleeding or other non-life-threatening problems arising from fibroids.⁴ The sheer volume of hysterectomies in the U.S. begs the question why so many women “elect” to have this procedure. Although many fibroids can be treated without hysterectomy, it is rare for providers to discuss or recommend these alternatives to their patients. When women receive

inadequate (or no) choices in the face of constantly unpleasant symptoms, the reason so many women are having hysterectomies becomes evident.

A few months ago, I started hearing commercials about alternative fibroid treatments on the “urban” focused radio stations I sometimes listen to. Although the ads did not specifically say what the alternative was, calling the number or going to the website given revealed that the procedure was Uterine Artery Embolization (UAE). UAE is a relatively recent procedure that shrinks fibroids by blocking blood vessels to the uterus (which blocks the blood flow that allows the fibroids to grow). I was quite surprised that Black women were actually being marketed to, but it makes sense to target this audience. Black women suffer disproportionately from fibroids and are three to five times more likely to develop them than White women. We also tend to have larger, more numerous fibroids at diagnosis;⁸ fibroids seem to occur at a younger age and grow more quickly in Black women as well.⁹ Fibroids are the reason behind 30% of hysterectomies in White women and over 50% of hysterectomies in Black women.⁸

A 2009 study in the American Journal of Public Health examined 1,863 women and found that, between 2000 and 2002, 78% of the women having a hysterectomy were Black and 22% were White. Surprisingly, fibroids did not explain the difference in the higher hysterectomy rate for Black women. Even when the data were adjusted to account for factors like age, educational level, and location, the four-to-one ratio persists. Researchers suggested that the disparity was likely due to factors such as access to information about alternatives to hysterectomy and inadequate provider communication with Black patients.¹⁰

Health disparities are not a new phenomenon — especially when it comes to level of health care and access to services that Black women receive — so the radio ads made me both pleased and skeptical. On one hand, I was happy that the ads acknowledged that a fibroid diagnosis does not automatically mean one has to have a hysterectomy, and knew the ads would reach a number of Black women who would benefit from this message. On the other hand, I wondered why, all of a sudden, medical institutions cared about Black women’s high rates of unnecessary hysterectomy. What was the catch? Why were we specifically being targeted, and which particular hysterectomy alternative was being touted?

I still don’t have a definitive answer why Black women have become a marketing focus for fibroid treatments. Maybe it is due to the realization that targeting Black women could create a lucrative market. After all, the statistics speak for themselves: why not offer services and products to a relatively untapped group that might benefit from this treatment, especially if one is offering a new and exciting technology. But, what’s odd is that the treatment the ads promoted is actually not a new and exciting alternative. Uterine Artery Embolization has been around since 1997, but we are only now seeing marketing for it, at least on “urban” radio stations. UAE (sometimes called Uterine Fibroid Embolization) is one of six treatment options for fibroids that do not involve hysterectomy. (Others are Myomectomy, focused ultra-sound, GnRH agonists, Myolysis, and Cryomyolysis. For a complete description of fibroid treatment options, visit <http://nwhn.org/fibroid-treatment-options> [2]).

Progress has been made in reducing the number of hysterectomies and helping women find alternatives that work for them. But, but there is still much work to be done to understand what causes fibroids and how best to treat them. Research estimates that up to 30% of all women of childbearing age will be diagnosed with uterine fibroids, but as many as 77% of women of childbearing age could have fibroids, since many women are asymptomatic. More research is

needed to understand fibroids’ root causes — especially given the significant racial disparities in women who experience this condition.¹¹ In addition, women need more information about all options for treating fibroids, since the Network believes the majority of hysterectomies performed in the U.S. are medically unnecessary. Women need information that helps them explore all options before they choose hysterectomy — although they may need to seek several opinions before finding a health care provider who is willing to discuss alternatives to the procedure.

In 2000, the Network testified at the Food and Drug Administration (FDA) proceedings to help specify study requirements for devices used to treat uterine fibroids. We made the point that gynecologist education and patient communication are important pieces of this puzzle and need more attention. As more alternatives for fibroid treatment emerge, I hope there is a particular focus on options that preserve fertility. Currently, Myomectomy is the only option that enables women treated for fibroids to bear children without using assisted reproductive technologies like in vitro fertilization. Better treatment options — as well as prevention data — need to be the next chapter in the story of U.S. women, fibroids, and hysterectomy.

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