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Factors That Delay Diagnosis of Uterine Fibroids and Endometriosis: The Demographic Divide

Announcer:

Welcome to CME on ReachMD. This activity, entitled "Factors That Delay Diagnosis of Uterine Fibroids and Endometriosis: The Demographic Divide" is provided by Omnia Education.

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Dr. Marsh:

Fibroids became part of my life quite a while before starting medical school or residency in OB/GYN. They were a condition that I learned about, quite frankly, as a young child. Many of my mom's friends, as well as some family members suffered from fibroids and ended up having surgery. So I remember as a young child, going to my mom's friends' homes, taking food, checking in on them, and hearing this term "fibroid." And quite frankly, often hearing that tied with the term hysterectomy, which I didn't know what it meant, but I just knew that it was going to be an opportunity for my mom to cook some delicious food and to take it to people that were near and dear to her heart and near and dear to my heart. As I got older, and certainly as I entered the medical profession, I quickly learned what the fibroids were and the treatment options, which were all too often surgery and quite frankly hysterectomy. And I think it was at that point that I really decided that it was a condition I wanted to study because I also learned that there were racial disparities with fibroid prevalence, fibroid impact, and also that there were disparities, that I learned later on, in terms of access to care and options for treatment. So it's a disease that I have been fascinated with, kind of scientifically and pathophysiologically, but it's also a disease that's been a part of my life since I was much younger and that I've seen family members and close family friends suffering from for decades.

Dr. Shulman:

Your know your story just gives me the chills. To have taken that experience as a young child and to have used that to have become the incredible clinician and researcher that you are really is a wonderful story, not just for people thinking about going into medicine or healthcare, but for anybody to use that kind of childhood and adolescent experience to go forward.

Women of color are disproportionately impacted by uterine fibroids and endometriosis. Issues of race and ethnicity unconsciously influence patterns of clinical care and referral. Today it's a great pleasure to be joined by a true expert in health disparities, Dr. Erica Marsh from the University of Michigan, who I've had the pleasure of working with and knowing now, actually, more than a couple of decades. Dr. Marsh, welcome. It's great to be here with you today.

Dr. Marsh:

Thank you so much, Dr. Shulman. It's always good to spend time with you, especially talking about topics that are near and dear to both of our hearts.

Dr. Shulman:

Let's talk a little bit about that condition that you were first introduced to as a young child: fibroids and perhaps also a bit on endometriosis. Can you talk a little bit about why it's so important for patients and providers to know about these two particular conditions?

Dr. Marsh:

Why do we care so much as, women's healthcare providers, about fibroids and endometriosis? The bottom line is that we care about them because of their prevalence and because of their impact on patients' quality of life. Just starting with fibroids, we know that fibroids are highly prevalent and that by the age of 50, 60%-70% of anybody who's born with a uterus is likely to have a fibroid. Now, they all won't be symptomatic from fibroids, but they will have them. Today we're talking about leiomyomas, what are more commonly called uterine fibroids, which are, again, noncancerous tumors or benign tumors that grow in the wall of the uterus. And they can vary in size from microscopic but they can grow as large as 40 centimeters in size.

In many patients who have fibroids, they have no symptoms at all, but in anywhere from 30%-50% of individuals with fibroids, they will have symptoms. And those symptoms are most commonly heavy menstrual bleeding. They can also include severe cramping or pain with periods, bulk symptoms from having a very enlarged uterus and that uterus pressing on the bladder or on the bowel. There are some patients that have infertility or challenges getting pregnant because of fibroids. And there's some patients who've had multiple pregnancy losses. I think one of the most concerning statistics is that they are the leading cause of hysterectomy in the United States. More than any gynecological cancer, it's fibroids – a benign condition – that's the leading cause of hysterectomy.

Endometriosis is much less prevalent. It affects closer to 10% of women in the reproductive age window, but for the patients that it affects, it is just as problematic and just as disruptive. The more common symptoms associated with endometriosis include chronic pelvic pain, particularly pelvic pain during the menses. And we also see a significant impact on fertility. The word "endometriosis," it's derived from the endometrium. Sometimes the stroma and glands end up on the outside of the uterus, and there are a lot of theories as to how that happens. That tissue ends up outside of the uterus and implants into, most commonly, the ovary, the fallopian tube, but sometimes that tissue can be found in far away places like the lung, the nasal cavity. During the period, that same tissue can respond in the same way that the endometrium responds to the changes in hormones that take place during the period and cause inflammation, pain, and impaired fertility.

Dr. Shulman:

That truly was one of the best overviews. You and I both understand that those similarities in clinical presentations can make for a very challenging assessment, diagnosis, and therapeutic intervention. What can you tell us about the disparities that occur when these symptoms occur in women of color and in women who have been historically underserved in the medical community?

Dr. Marsh:

Starting with fibroids, the most common presenting symptom with fibroids is going to be heavy menstrual bleeding, whereas the most common symptom with endometriosis, is going to be pain. That's really the distinction. In terms of racial disparities, I want to start by saying that in the data that I present, most of it will focus on White and Black women, and that's not to say that other groups are less important or unimportant. Asian ancestry, Latinx, and Hispanic women, Native American patients, as well. So most of what we're going to talk about in this session is going to focus on White and Black women for that reason. Whereas the overall prevalence of fibroids is somewhere, let's say, 65%-70% by the age of 50, in Black women that prevalence is closer to 85%-89%. So a pretty significant difference there. We also know that Black women are more likely to undergo hysterectomy and myomectomy than their White counterparts. The data show that they're a little more than 2 times as likely to undergo hysterectomy and almost 7 times as likely to undergo myomectomy for their fibroids. Some studies that we did in a younger cohort of women, as well as others, showed that Black women also develop fibroids at an earlier age, and the onset of the disease is much earlier in African American women. We looked at a cohort of women between 18 and 30 years old, we found that about 27% of Black women in that very young cohort had fibroids. Now they weren't symptomatic from them, but they were present on ultrasound. And that compared to 6% of White women who had fibroids in that same age group. So we know that the age of onset is earlier in Black women, that a higher prevalence overall even at the earlier ages exists in Black women. We also know that Black women report a higher impairment in terms of quality of life, in terms of impact of fibroids, and are more likely to report feeling self-conscious about their appearance due to fibroids, as well as having more significant impacts – emotional health impacts from fibroids, including anxiety and depression. Now, when we think about endometriosis, I would say there's less data in the health disparity space. Endometriosis is associated with severe pain and infertility — one of the challenges is its difficulty in diagnosis. Studies have shown that patients wait, on average, 7 to 9 years before getting an appropriate and correct diagnosis of the source of their pain. We don't want to have our patients floating through a healthcare system where they're not being treated appropriately because they don't have the appropriate diagnosis. So we need to do better about that, but we also know that patients are making an average of 7 visits to their primary care docs before being referred to a specialist for endometriosis.

I think one of the most concerning disparities with endometriosis is that it has historically thought to be a condition that really affects White affluent women – not Black and not women from a lower socioeconomic class. That Black women who present with pain are often underdiagnosed with endometriosis, and one study has shown that Black women are actually 50% less likely to receive a diagnosis for endometriosis than White women. We don't know the exact cause for that, but it certainly raises some concerns in terms of racial

disparities and potentially a role of racism and how racism's expressed in healthcare and the impact that that has. So I think we have work to do in making the diagnosis of endometriosis, of understanding that women of all backgrounds could have endometriosis, and that it needs to be on the differential diagnosis list for any patient, regardless of race and regardless of socioeconomic class, who presents with certainly cyclic pelvic pain, but even chronic pelvic pain as well. And that treatment options for those patients need to include important treatment for endometriosis.

Dr. Shulman:

The diagnosis, the treatment, the differentiation of these symptom constellation that clearly leads to profound morbidity, that health disparities in the underserved community are going to lead to considerably worse outcomes, and your work has highlighted that over the course of the last decade.

For those just tuning in, you're listening to CME on ReachMD. I'm Dr. Lee Shulman, and here with me today is Dr. Erica Marsh. We're just about to talk about broader issues of fibroids and endometriosis treatment and the disparity seen across populations.

Can you give our audience a broad overview of how do we level the playing field? How do we get these treatments to women without them having to come to the office 7 to 8 times, without them having to convince a clinician that they are in pain or having problems conceiving or are unable to enjoy life? How do we go about this with the considerable – the expansion of nonsurgical, of medical therapies that have truly been shown to change the role of clinicians and improve outcomes?

Dr. Marsh:

I think it's interesting that even though these conditions have very different pathophysiologies, they have very similar categories of medical treatment. The overlap is pretty significant and includes medications that are GnRH agonists, which are medications that essentially allow healthcare providers to indirectly – or shut down the hypothalamic-pituitary-ovarian axis. We also have hormonal interventions, specifically locally acting progestins as well as systemic progestins to be helpful with some of the heavy menstrual bleeding that we see in fibroids. With endometriosis, there's a role for selective estrogen receptor modulators. And there's also a newer category of medications called GnRH antagonists that have been approved for treatment of fibroids and, in some cases, in the treatment of endometriosis as well. So I think, again, that is a newer class. I think it differs from the older medication class of GnRH agonist, in that the GnRH antagonists have an effect much more rapidly than the GnRH agonists. The GnRH antagonists function by very rapidly downregulating that hypothalamic-pituitary-ovarian axis. So we're actually really excited about that class. Another novel aspect of that class is that it can be taken orally. It does not have to be injected or inhaled. So it's much more convenient, and when they start it, they can have the reassurance that it's going to have impact very quickly. I think there's just a lot of excitement about this newest class of drugs, the GnRH antagonist, their ease of use and rapid onset.

Dr. Shulman:

Erica, you've brought up really the fascinating new development in the treatment of endometriosis, the GnRH antagonists. What about the role of this class of drug in women who want to maintain their fertility and avoid hysterectomy or any other intervention that would impact their ability to conceive down the road?

Dr. Marsh:

I think, and that's a key reason why GnRH antagonists as a class is an important intervention and innovation for patients who do want to maintain their fertility. This class of medication can be taken orally daily and has a relatively rapid timing of onset. But also, when you stop the medication, the time to be able to get pregnant is relatively short, so I think an ideal therapeutic agent for patients for whom that's a goal.

Dr. Shulman:

Erica, can you share your one take-home message with our audience?

Dr. Marsh:

I think it's important for providers and patients to understand that even though these conditions can feel quite common in the gynecological setting, they're not common for patients, and that every patient is unique and different, and every patient deserves a thoughtful evaluation and treatment plan. I think it's easy for us, particularly in our social media culture, for patients to kind of see something and – see a treatment plan that worked for one person and think, "Oh, this is going to work for me." And it's easy for us as providers to kind of get in a mode where we say, "Okay, this is how I treat endometriosis. This is how I treat, fibroids." I think it's important to remember that every patient is different, every case is different, and it's really important to have shared decision-making and thoughtful counseling with regard to treatment options for both of these conditions so that the patient can feel satisfied that they understand and have received information on all of the options, that they're making a treatment choice that is best for them and takes into account their symptoms, their personal goals, their overall health standing as surgical candidates or not standing as surgical candidates, and again allows them to make a decision that is best for them. And a decision in which their provider can take part and

share in that decision-making.

Dr. Shulman:

To summarize, clearly one size does not fit all, especially with these challenging conditions, and the sooner that we can level that playing field — getting these interventions to women throughout our communities — the better that we're going to have clinical outcomes in all women.

Erica, unfortunately, that is all the time we have today, so I want to thank our audience for listening and joining us, and truly to thank you, Dr. Marsh, for joining us today, for sharing all of your valuable insights. It was absolutely great speaking with you today.

Announcer:

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