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Overcoming Bias and Stigma in Endometriosis: Strategies for Inclusive, Patient-Centered Care

Announcer:
You're listening to *Advances in Women's Health* on ReachMD, and this episode is sponsored by Sumitomo Pharma. Here's your host, Dr. Charles Turck.

Dr. Turck:
Welcome to *Advances in Women's Health* on ReachMD. I'm Dr. Charles Turck, and joining me to discuss how we can overcome bias and stigma in endometriosis management is Dr. Whitney Ross, who's an Assistant Professor of Obstetrics and Gynecology in the Division of Minimally Invasive Gynecologic Surgery at Washington University in Saint Louis.

Dr. Ross, thanks for being here today.

Dr. Ross:
Thank you so much, Dr. Turck. It's great to be here.

Dr. Turck:
Well, to get us started, Dr. Ross, how have historical misconceptions and biases around endometriosis treatment shaped our prescribing habits?

Dr. Ross:
So with endometriosis being a hidden condition, we really have to think about the steps for a patient to go from having pain and painful periods to then getting a diagnosis. So, the first thing is, as clinicians, we have to believe the symptoms and believe that they're severe enough to intervene.

So looking at historical misconceptions, it's not very long ago that women were diagnosed with hysteria, and anytime that they were expressing symptoms or distress that weren't concordant with social norms, then the treatment for that would've been to have a hysterectomy and remove their reproductive organs. So I think there's this historical bias that women aren't reliable historians or aren't to be trusted. We really have to get over that source of historical bias to be able to believe patients and believe what they're telling us.

And the second source of bias is that a lot of the early endometriosis studies were conducted from a practice that was in an affluent community of white women, so endometriosis was called the career woman's disease. So for someone who doesn't look like that initial patient population, there's this conception that they can't possibly have endometriosis because they aren't a young, affluent, white career woman.

So there's been lots of misconceptions in textbooks and articles over the years that have been perpetuating this source of bias. Many people don't even realize that it is even a source of bias, or that it's not factual. So I think that that's the other piece— that there's even more barriers for African American women and women of color to be able to be diagnosed and even be prescribed any type of treatment.

Dr. Turck:
And what can you tell us about some of the pros and cons of the different treatments for endometriosis?

Dr. Ross:
So the most common medications that people have tried are both control pills. And while these are great for some people, a lot of people also have side effects. So the most common side effects with birth control pills—we're all super familiar with them as gynecologists, so I'll skip over that. I spend a lot of time, in terms of counseling, focusing on the progestin-only methods because a lot of

people will tolerate progestin-only methods. Norethindrone is one that's FDA approved specifically for endometriosis, and we can start on really low doses and work up. I think people are really concerned about mood side effects, weight gain—those are some of the big side effects that I end up talking to patients a lot about. So some people will actually have those side effects with traditional birth control but not so much with the progesterone-only methods, especially at low doses.

The levonorgestrel IUD is another wonderful option for people who have had systemic side effects to birth control pills, or maybe they didn't tolerate the systemic progestins, so then we're getting local effect to the uterus. So that way, people who have had a lot of the systemic side effects might be great candidates for an IUD to get local control of the uterus and the bleeding and the dysmenorrhea. Some people, then, will get a lot of cramps from the IUD, and I counsel people upfront about the IUD that it's great for some people, but not so great for other people. And then the other thing with the IUD is because it is so local, there are people who have endometriomas or issues with recurrent ovarian cysts—that's not going to give enough effect on the ovaries to give suppression. For better and worse, we want it to not have the systemic side effects, but it also won't give us the ovulation control that some of the other systemic agents will.

And then the final main class that is approved for endometriosis is the GnRH modulators. So historically, it's leuprolide—that's a GnRH agonist that induces a temporary menopausal state. That can be really helpful for some people, but it has very intense menopausal side effects—mood side effects in up to 20 percent of people. So it's not a medication I end up prescribing very much because it's poorly tolerated. I explain to patients that there's a newer category of GnRH antagonists, then there's both combination—the relugolix with estrogen/progesterone—and elagolix as monotherapy. And the elagolix I end up prescribing quite a bit because there is a lower dose that's a once-daily dosing that's approved for two years, and then there's the twice-daily dosing that's approved for six months.

But then we spend a lot of time talking about the side effects. The profile can be very different for elagolix than for norethindrones and local hormones, though each fits a different need in terms of who's tolerated what. So you can navigate and choose based on what people have tried before and what the side effects were, and then pick the one that's best concordant.

Dr. Turck:
For those just tuning in, you're listening to *Advances in Women's Health* on ReachMD. I'm Dr. Charles Turck, and I'm speaking with Dr. Whitney Ross about how we can break down bias and stigma in endometriosis care.

So, Dr. Ross, I'd like to zero in on strategies for counseling patients on their treatment options. What are some of the most common concerns you hear about hormonal therapies, and how do you navigate those conversations?

Dr. Ross:
Absolutely. One of the problems with the different hormonal therapies is each of them has different side effects, and we're stuck with a trial-and-error approach. Some medications work great for some people, and someone who might on paper look like a similar profile of a patient might have a horrible response to it. So the first thing is just acknowledging people have really bad experiences and side effects with hormonal therapies, and then walking through the different types, whether it's combined estrogen and progesterone, teasing out what they've tried in the past, and then moving to a category that's different than what they've tried before. And also, there's a big role for education and explaining that not all estrogens are the same and not all progesterones are the same—and while there's risks with trying a different medication, understanding why there's a chance that this one might be different than before.

Dr. Turck:
Now, what role does education play in increasing treatment acceptance and adherence?

Dr. Ross:
So when anybody's starting a treatment or any type of medication, it's important to know, what is our hope that the medication is going to do for them? What is the pathway? What's the expectation? Is this going to be something that's going to start and help right away? Is it going to be a wait-and-see for three months? Is it going to be like with a levonorgestrel IUD where we'll place it, but it might be 12 months until we see max effect? It's incredibly important to have a very straightforward discussion about the pathway with this medication. What are the things to be on the look-out for? And then when should they be reaching out to say, "Okay, we've tried it. It's not working. When do we move onto the next thing?"

I also think it's incredibly important to just have a plan A of what's going to happen, and then a plan B and a plan C, and that the patient is engaging with setting up what the different plans are and knowing what we're going to do when things are going well.

Dr. Turck:
And finally, Dr. Ross, bringing this around full circle, do you have any key takeaways on how we can address the persistent challenge of bias in endometriosis care?

Dr. Ross:

Yeah. One of the important things, from the clinician perspective, is recognizing that all of us have sources of unconscious bias and realizing that while there are different patterns of symptoms and those help us diagnose diseases, every patient's journey is a little bit different. And being open to taking the symptoms that each patient expresses to us at face value so that then we help them get a diagnosis.

I think that it's helpful to understand historically why these sorts of bias happened so that we can challenge ourselves day-to-day as individuals, but also as practices and societies and as a culture to then move away from where we've been historically and then provide better care now and going forward.

Dr. Turck:
Well, with those key insights in mind, I want to thank my guest, Dr. Whitney Ross, for joining me to discuss best practices for overcoming bias and stigma in endometriosis care.

Dr. Ross, it was great having you on the program.

Dr. Ross:
Thank you so much, Dr. Turck. It was great to be here.

Announcer:
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