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Creating a Practice Environment That Enhances Healthcare Equality for All Patients

Announcer:
Welcome to CME on ReachMD. This activity, titled "Creating a Practice Environment That Enhances Healthcare Equality for All Patients" is provided by Omnia Education.

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Dr. Shulman:
Healthcare disparities exist in the management of endometriosis. While many are related to social determinants of health, or SDOH, physician and patient biases may also impact the quality of healthcare received.

Today, we will be joining a discussion with Dr. Linda Bradley and Dr. Melissa Simon, in which they'll be addressing strategies for creating a patient-centered practice environment.

This is CME on ReachMD, and I'm Dr. Lee Shulman. I'd like to first welcome Dr. Bradley to our program today.

Dr. Bradley:
Thank you very much, Lee.

Dr. Shulman:
And in addition, joining us from her home, I'd like to welcome my colleague, Dr. Melissa Simon.
Dr. Simon:

Thank you so much, Lee. It's so nice to be joining you and Linda today.

Dr. Shulman:
Linda, I'm looking forward to your interview with Lauren Kornegay, executive director of the nonprofit foundation, Endo Black. But let's begin our discussion with a question. Healthcare disparities exist in the management of endometriosis. Can you provide some insight into these disparities?

Dr. Bradley:
Sure, Lee. Love to cover this with you in some detail. As described by Bougie and colleagues in 2019, and even updated in 2022, they looked at disparities. And it encompassed things like looking at racial and ethnic prevalence estimates, various disease presentations between different ethnic groups, the range of treatment provided – who got what, when, and why – and more importantly, approaches to long-term management.

Dr. Shulman:
So, Linda, what's the basis for many of these disparities?

Dr. Bradley:
Another good question. But you know, disparities that cross racial and ethnic boundaries often have an incorrect historic basis and

factually are unsupported. Sometimes, it's been said that the rates of endometriosis is lower in black women than white women. And there's also a similar bias for Hispanic women. Asian women are 50% more likely to have endometriosis than white women. And diagnostic bias begins at the first clinical presentation of the disease to a physician or healthcare team.

Additionally, evidence for bias-associated index of suspicion derives from evidence that there is little to no difference in endometriosis diagnostic rates across racial and ethnic groups when patients are presenting with infertility issues. Why? Because endometriosis is a differential diagnosis for infertility, and doctors think about it for everybody.

Dr. Shulman:
So do we also see these disparities when it comes to treatment?

Dr. Bradley:
Yes. The impact of racial and ethnic bias extends to treatment. Data from Westwood and colleagues in 2023 suggests that white women are more likely to get a referral to a minimally invasive surgeon, compared to a non-white woman. White women are also more likely to receive a minimally invasive treatment procedure, robotic surgery, laparoscopic surgery, versus open abdominal surgeries than non-white women. And white women will have and experience fewer complications than other races. In addition, they have less mortality. So we can see, just broadly, these disparities in treatment, surgery, and complications.

Dr. Shulman:
Linda, that's a great overview. But I understand that we have a guest here today who's going to shed some light on many of the issues that you just mentioned.

Dr. Bradley:
Lee, we are grateful to have Lauren Kornegay. Lauren is founder and executive director of the nonprofit Endo Black, Incorporated. Her mission, and that of Endo Black, is to raise awareness about endometriosis, advocate for women of color so they receive a timely and correct diagnosis, followed by patient-centered care.

Welcome, Lauren. Thanks for joining us today.

Lauren:
Absolutely. Thank you so much for having me.

Dr. Bradley:

Lauren, could you please describe your endometriosis journey and how that motivated you to create your nonprofit foundation, Endo Black?

Lauren:
Absolutely. I was diagnosed with endometriosis March the 18th, 2011. After being diagnosed, I took it upon myself to do more research to learn about my disorder. In doing that, I actually became more confused. And one of the things that my mother always taught me is if you're going to complain about something that you need to find a resolution. So that's what I did.

We started Endo Black as an Instagram page for my selfish reasons, of course, to learn more about my body and learn more about endometriosis. But upon doing that, we were able to connect with so many women across state lines who dealt with endometriosis, struggled with it, and weren't sure if they even had it, but they had some concerns. They encouraged me to start the nonprofit. So we started the nonprofit in 2019. We've come up on 5 years as April the 19th, and we're really excited about that.

Some of the things that we've been able to do with Endo Black has been tremendous. We have our Ambassador's Program where we bring on women who are sisters, mothers, daughters. They all have endometriosis, and they're learning how to be advocates for themselves. But in the midst of learning how to be an advocate for themselves, they're also a part of committees where they're looking to do research, policymaking, social impact events, fundraisers, and so much more.

Endo Black has also had the opportunity to host African American endometriosis workshops in partnership with our library in Prince George's County. We've had the opportunity to go to high schools in Baltimore County, Prince George's County, and hopefully soon in DC to provide period care kits, where we're trying to educate young adults on period care, but also encouraging them to voice their opinions to their parents and also how to advocate for themselves when they're in pain, just in case they're dealing with adenomyosis, endometriosis, fibroids, or PCOS. So we've been able to do a lot of different things. We're so grateful. We've had our conference. We just hosted the fourth annual conference, earlier in March of this year, in an effort to raise awareness about endometriosis but also form an amazing sisterhood among women, across state lines again. So we've had the opportunity to do so much, and we're really, really excited that we're going to continue to do things.

And lastly, I would love to share that we continue to do research in the community. Currently, we're doing research with George Mason University, having the opportunity to work on research such as the first-, second-, and third-generational women who have endometriosis. We're also looking at supporting teenagers, ages 14 to 24, with a video game that we are hoping to build. The research study for that is called SurrEndo.

So we have a lot of opportunities to do a lot of work, and we love that people continue to come out to us for support. So we just try to provide resources, tool kits, and information as needed, because we know that when I was struggling to find that information, I had a rough time. So we want to be able to assist people as they come to us.

Dr. Bradley:
That's amazing, Lauren. What are the healthcare inequities your community of women typically encounter, from delayed diagnosis to misdiagnosis, even to the lack of patient-centered care?

Lauren Kornegay:
Thank you for that question. The challenge is, you actually mentioned some, which is the misdiagnosing, delayed diagnosing. That actually is very, very impactful in our community. It causes a lot of confusion. I also like to share that there's not a lot of resources for African American women who may be struggling with endometriosis. And then lastly, there's not a lot of research for women who look like me. And with Endo Black, we're trying our best to actually hit on all of those needs and unmet needs currently with all of the programs that we have going on.

However, for example, at some point, the American Medical Association shared a research study that took place in 2016 that actually stated that 50% of the medical trainees believe that black people had less nerve endings than anybody else. So when you have things like that, when you have statistics like that of medical trainees believing things like this, it could be very detrimental to the community. It can cause a lot of difficulties when it comes to just making sure that black people get the help that they need.

So when you have black women or black people going to medical professionals seeking assistance and they are being told that they are only drug seeking or they're being told that they can handle the pain, it becomes very difficult to trust a medical individual who's supposed to be there to give us that support. And it makes it very difficult for people to continue that trust, to continuously go back to these people who are telling them things that they know aren't true. Unfortunately, this isn't something that's just targeted with black women; this is a thing with all women who have endometriosis. And we've seen it multiple times. When you see information that does not include people that look like you, you kind of write it off. And that kind of makes it difficult to get accurate diagnosing when we don't have accurate information out. So it's really important to make sure that we have that research on black women, Hispanic women, women of color in general so that when women are dealing with these issues when women are dealing with these issues, we're able to get the answers that we need to get. That way, they can get the help they need to get. They can get the care they need to get. They can also get the mental health therapy that they need to get when it comes to all of these different things.

We talked about how it's misdiagnosed and delayed diagnosed, and that is one of the reasons. Another reason is just education. We don't know what symptoms look like for endometriosis sometimes, and that's why research plays a critical role, when we don't understand the specific symptoms of endometriosis. There are young girls currently who may be dealing with endometriosis symptoms and they don't even know that they may have endometriosis. There are currently women right now who are walking around with symptoms that could be mild, severe, or minor, and not even know it, to the point where they're so confused, where they think that, you know, this headache or this migraine, or unfortunately, vomiting is not a symptom, because there's no education on the fact that this is a full-body disorder. So education is really key in helping with misdiagnosing and delayed diagnosing; research assists with that. And lastly, but not least, resources, just making sure that we have resources in the community.

Dr. Bradley:
Lauren, is there a message you would like to offer all women, regardless of racial or ethnic background, to motivate them as they traverse their endometriosis life journey?

Lauren:
Absolutely. I always say this: extend yourself grace. If you are trying to get diagnosed, if you have been diagnosed, or if you're just doing research, extend yourself grace. This is not an easy process. There is no rule book or guidebook to any of this information that we're sharing. It's imperative that you take your time. This is a new journey that people are going through. And you have to understand that endometriosis is not you and it is just one part of who you are as a person. Do not let this consume you, and do not let this ruin all of the great memories and the great life and the great things you have coming towards you. So again, extend yourself grace in this process, take time, do not overwhelm yourself. And lastly, advocate for yourself. Again, there's no rule book to this. Take your time and advocate for yourself, because if you don't, no one else will.

Dr. Bradley:
Lauren, I just want to thank you for joining us today, and we are proud of what you're doing. For those of you at home, you can easily find Endo Black at endoblack.org.

Lauren:
Thank you.

Dr. Bradley:
Lee, she's a remarkable woman.

Dr. Shulman:
She sure is.

For those just tuning in, you're listening to ReachMD. I'm Dr. Lee Shulman, and today we are joining a discussion with Dr. Linda Bradley and Dr. Melissa Simon. They are just about to delve further into the strategies that help to create a patient-centered practice environment that enhances the delivery of quality healthcare to all patients.

Linda, thanks so much for a great interview, a really insightful interview in what women, regardless of racial or ethnic background, have to deal with traversing the diagnostic and therapeutic challenges of endometriosis.

Let's now turn back to Dr. Melissa Simon, who's been waiting patiently. Melissa, what are some clinical strategies to overcome bias in clinical practice?

Dr. Simon:
Thank you so much for that question, Lee. First and foremost, we have to work to understand what our personal biases are. And all of us actually do have biases, many different ones, and it's important to just be aware and learn how to manage them. We have to, for example, avoid using race and ethnicity to place different population groups into generalized health-risk buckets. Just because a person looks or shows up in the world in a particular way, regardless of their color of skin or their height or whatever characteristic it is, it doesn't mean a particular diagnosis is automatic or something should be overlooked.

And we have to really also be aware that endometriosis has many varied presentations across different races and ethnicities, as well as where a woman is in her endometriosis journey, that can impact how you see or diagnose a patient. And we really have to be open to considering endometriosis as a potential diagnosis when our patients are of reproductive age and presenting with one or more of the following symptoms, such as pelvic pain or menstrual or non-menstrual pain, abdominal pain, dysmenorrhea, dysuria, dysgeusia, depression, anxiety, sleep disorders, loss of self-worth. Infertility is a big one as well, poor personal or family relationships, decreased work productivity, and there can be many more. We just have to be open and listen because a woman really knows her own body.

Dr. Shulman:
Melissa, putting this all together, what single key point would you stress to your colleagues to help them overcome any biases that could lead to delayed diagnosis of endometriosis?

Dr. Simon:
I emphasize what I already said, but in addition, maintain that high index of suspicion for endometriosis and refer patients for ultrasound and/or MRI imaging to assist with that diagnosis. And that should always be top of mind.

Dr. Shulman:
Melissa, thanks so much.

Linda, let's turn to another issue when addressing healthcare disparities in our clinical practices. I'm referring to SDOH, or social determinants of health.

Dr. Bradley:
Well, let's talk about it for certain.

Healthy People 2030 defines SDOH as follows. Social determinants of health are the conditions and the environments where people are born, live, learn, work, play, worship, and age that affects a wide range of health functioning and quality of life outcomes and risk. The *American Journal of Managed Care* in 2024 indicated that up to 80% of clinical outcomes are related to nonclinical socioeconomic barriers to optimal health; 40% of the issues that arise are due to social and economic factors like education, income, family support, social support; 30% are due to health behaviors: substance abuse, obesity, overweight, tobacco, exercise; 10% are environmental: the air and water quality, housing, and transit; and 20% are due to clinical care, meaning access to care, quality of care, and even follow-up care practices.

Dr. Shulman:
Linda, thanks so much. But if I get what you're saying, these biases that physicians and patients bring to the overall healthcare system actually superimpose upon even more difficult social determinants that really require us to address.

Dr. Bradley:
Exactly, Lee.

Dr. Shulman:
Well, what are we doing about SDOH at an organizational level?

Dr. Bradley:
Well, we're going to hear more about this shortly. But again, there's something called the Health Equity Index, or HEI, and this has been defined by CMS. It's going to likely impact non-CMS patients in the future. The HEI grades organizational response to the social determinants of health within the patient population that's being served. This whole issue of HEI and SDOH initiatives is very broad and it's ambitious. It's an ambitious effort that will require time to develop and to implement.

Dr. Shulman:
Linda, thanks so much. Let's turn back to Melissa.

Well, Melissa, while the broader application HEI and its application to SDOH is still in its early development, how can we as clinicians get a head start in this process in our clinical practices?

Dr. Simon:
Thank you so much for asking that, Lee. First, the individual clinician and the clinical care team should really seek to gain a better understanding of all of the socioeconomic and environmental factors and barriers to care, insurance issues, payer status that patients face, and in terms of racism for certain racial and ethnic minoritized groups. And these issues really do present substantial significant challenges in patients’ engagement in care, their ability to adhere to care plans, and their ability to get the appropriate treatment that they need to really prioritize their health.

And we really have to look at our administrative processes as well in our clinic in terms of referrals, not only just to other specialists or healthcare providers, but to other organizations and community organizations or wraparound services that are required to help an individual patient overcome some of those social and economic factors that can hinder health.

And we can use such indexes such as the Center for Disease Control and Prevention Social Vulnerability Index. We can be better identifiers of transportation needs and connect people to ride support. We also can be mindful of how many visits a patient really needs to the clinic versus a telehealth visit, as an example. We have to be mindful of issues such as low health literacy and the level at which how much jargon is used in our day-to-day communications with patients and their caregivers or loved ones. And we have to more closely monitor care adherence and engagement in care, but that really is underpinned by how much our patients trust us.

And so to help in these efforts, we can use SF-36, EHP-30 questionnaires, for example, for our patients with suspected endometriosis.

Dr. Shulman:
Melissa, are there any other tools available to help us better understand the SDOH issues faced by many patients within our own medical practices?

Dr. Simon:
There sure are, Lee. They include such things such as the PRAPARE, or P-R-A-P-A-R-E. it's called the Protocol for Responding and Assessing Patients Assets, Risks, and Experiences. There's AAFP [American Academy of Family Physicians] tools. There's the CMS [Centers for Medicare & Medicaid Services] Health-Related Social Needs Screening Tool. And really, it's important to understand that SDOH issues faced by our patients have been long standing but are now hopefully receiving actionable attention that they deserve.

Dr. Shulman:
Melissa, thanks so much. Your insight into this is incredibly valuable for all of us who care for women, for whatever conditions they bring to our offices.

Unfortunately, that's all the time we have today. So I want to first thank our audience for listening in, to thank Dr. Simon at her home in Chicago, and to Linda Bradley here in our studio, for sharing their experience and insight. It was great speaking to both of you today.

Dr. Bradley:
Great with you also.

Dr. Simon:
Thank you so much, Linda and Lee. I really appreciated joining you today.

Dr. Shulman:
Thank you all for listening today and have a good rest of the day.

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