Transcript Details

This is a transcript of a continuing medical education (CME) activity. Additional media formats for the activity and full activity details (including sponsor and supporter, disclosures, and instructions for claiming credit) are available by visiting:
https://reachmd.com/programs/cme/its-not-just-black-and-white-seeing-the-full-spectrum-of-endometriosis-cases/26290/

Released: 08/09/2024
Valid until: 08/09/2025
Time needed to complete: 1h 44m

ReachMD
www.reachmd.com
info@reachmd.com
(866) 423-7849

It’s Not Just Black and White: Seeing the Full Spectrum of Endometriosis Cases

Announcer:
Welcome to CME on ReachMD. This episode is part of our MinuteCE curriculum.

Prior to beginning the activity, please be sure to review the faculty and commercial support disclosure statements as well as the learning objectives.

Dr. Bradley:
This is CME on ReachMD and I'm Dr. Linda Bradley. I'm joined today by Dr. Melissa Simon from her home. Welcome, Dr. Simon.

Dr. Simon:
Thank you so much, Dr. Bradley, it is great to be here.

Dr. Bradley:
We are joined today in the studio by Casey Joe Hinds, who will share her personal story and journey with endometriosis.

Casey Joe:
It’s a pleasure to be here, Dr. Bradley and Dr. Simon.

Dr. Bradley:
Great. Let's get to it, Melissa. Let's start with you. How does race and ethnicity impact the management of endometriosis?

Dr. Simon:
So race and ethnicity is really important with respect to the diagnosis of endometriosis in a unique way. So I want to make sure that everybody understands that race is not a biological variable, nor is ethnicity. It's a social construct, and ancestry really is more the operator with respect to biology. But race and ethnicity is what we see, so it's a phenotype, is how we show up in the world. And so race and ethnicity impact a lot of what audience members may know as social determinants of health, the experience of racism, the experience of bias, the experience of all those isms in many different ways, and especially over time. So there may be lack of access to care, access to knowledge about endometriosis, lack of acknowledgement of pain or other manifestations of symptoms of endometriosis due to the “isms” and the bias that different minoritized or racial and ethnic minoritized groups experience. So that's really where that health disparities and experience of who you are with respect to your race and ethnic identities play out in endometriosis.

So in terms of what's been described in 2019 by Bougie and colleagues, and then updated in 2022, in terms of assessing disparities, that really encompasses racial and ethnic prevalence estimates, various disease presentations, the range of treatment provided, and approaches to long-term management. So we know that these biases and these isms that I referred to, including structural racism and racism discrimination, all impact all of those aspects that drive disparities and especially disparities in endometriosis.

And they also have things like historical context that is really important to remember. And while we must move forward from history, we must never forget history and how it plays into the over decades’ experience of discrimination and racism, especially from some minoritized groups. So that’s really important to understand.

And in terms of biases with respect to facts and reporting, the rate of endometriosis is lower in Black women than White women. But again, Black women may never have had the opportunity to be heard about what their body is telling them and how they really feel, and those presentations of pain may have been discounted over time because of not feeling valued or heard within the healthcare system.

A similar bias exists for Latina women or Hispanic women, and Asian women are 50% more likely to have endometriosis than White women. And this diagnostic bias begins at the first clinical presentation of disease to a physician.

Dr. Bradley:
Melissa, what is the practical effect of diagnostic bias with endometriosis?

Dr. Simon:
You know, such bias often leads to a diminished index of suspicion for an endometriosis diagnosis by the clinician, kind of like what I was saying for earlier. The end result is delayed diagnosis or an incorrect diagnosis with unnecessary treatments. And the evidence for a bias-associated index of suspicion derives from the fact that there is little to no difference in endometriosis diagnosis rights across racial and ethnic groups when patients actually present with infertility issues. Why? Because endometriosis is a differential diagnosis for infertility!

So the impact of racial and ethnic bias extends to treatment and management of endometriosis as well. We know this from an article by Westwood and colleagues from 2023. We know that White women are more likely to receive a referral than non-White women to someone regarding endometriosis care and treatment. White women are more likely to receive minimally invasive approaches than non-White women. And White women also experience fewer surgical complications and lower mortality than other races with respect to endometriosis.

Dr. Bradley:
Thank you, Melissa. Now let's turn our attention to Casey Joe Hinds who will tell us her personal story and journey with endometriosis.

Casey Joe:
So I was diagnosed with endometriosis in 2018. I actually was just headed to the doctor to get birth control. However, there was a concern with my stomach because it was really hard and large. So my doctor at the time, he was like, oh, I think you have a tumor in your stomach. Basically, after different tests, I had an MRI, we went to a different doctor. I was then told I had endometriosis through laparoscopic surgery. I had never heard of endometriosis. I didn't know how to spell it. I didn’t know what it was. But that began this whole journey of advocacy because once I learned more about it and how many women are affected by it, I felt that it was important to share as much knowledge as I possibly could on social media.

Dr. Bradley:
Thank you. How do you think race and ethnicity and even potential disparities affect the diagnosis and even maybe management of women with endometriosis?

Casey Joe:
So unfortunately, we know as Black women, and I am half Latina, so Hispanic women deal with it as well, we don't get paid as much as other races may, so that can affect our insurance; that can affect just the income coming into our households. And unfortunately, we don't always have the option to find the doctors that care about what we are dealing with, to care to care about even our condition. So I think race plays such a huge role because we oftentimes don't have the resources that other women have, and a lot of times we deal with more medically gaslighting situations, doctors kind of telling us, hey, this is just your body, which is something that I experienced. I went through about 5 different medical professionals who all just kind of pushed me to the side and let me know that my period was normal, when indeed it was 10 days long every 2 weeks.

Dr. Bradley:
That's a lot. So how do women of color, biracial women, become empowered as it relates to symptoms of endometriosis?

Casey Joe:
I think it's best to, one, have somebody there to advocate for you. I think that is always a great step. I think having somebody there that can speak on your behalf if you're feeling a little bit timid would help tremendously. I also feel that you shouldn't be afraid to kind of push back on your medical providers.

I think you need to ask the right questions. Do as much research as possible and don't take no for an answer if you feel that something is wrong from the patient standpoint. But when it comes to the medical professional standpoint, I think we need to understand that not all symptoms look the same, that we all experience something very, very different. And if we know that endometriosis can be part of the issue, especially when 1 in 10 women are dealing with it, that they need to, you know, rule that out before just saying, oh, that's just normal.

Dr. Bradley:
Sometimes language matters, the lexicon, how we speak, our tone, the words that we might use. And your advocacy position, again, looking at racial, ethnic disparities, are there any practical effects that you would say to a patient that you're teaching, like how to really advocate for yourself, the words, the tone, the methodology, in order to have a doctor or healthcare professional listen.

Casey Joe:
I'm going to be completely transparent. I kind of express them to be themselves. I think we're not the ones that been to medical school, we don't, you know, we are the ones that are just coming with our concerns. And with that being said, I think it is important to just be yourself and have a doctor maybe understand the way that you speak. I think having some type of relatability to your doctor is really important so they can kind of come to your level, because I'm not going to fully understand all of the big words, right? But I will say continue to do that research and learn certain things. Learn about endometriosis or fibroids or PCOS, or whatever the situation may be, so when you are presenting these questions, they know that you've done your research and that you're not just going to take no for an answer.

Dr. Bradley:
Excellent. Did you keep a journal in order to sort of share dates, times, the level of pain or discomfort, amounts of bleeding? Does journaling help women?

Casey Joe:
I think journaling can totally help. I'm a little unorganized and don't write a lot, but I do social media, so that became my journal. Filming videos on Instagram, YouTube, TikTok, and that's how I learned as much as I did, because me publicly putting that information out there, a lot of women were able to relate or maybe share tips or maybe ask me questions and see if that was their issue. I personally had such severe symptoms that I didn't need a journal because they were unforgettable in my opinion.

Dr. Bradley:
What would you want to say to a doctor, the next person of color that they see with symptoms? What would you like them to say back to a patient, echo back, and to do?

Casey Joe:
I hear you. I understand what you are feeling. Let’s rule out anything we possibly can. I think just hearing that alone would just bring so much comfort to patients, and actually do the work to do it. But I think a lot of times we feel intimidated, and we don't know what to say to doctors, and receiving that validation is extremely important. I think a little empathy goes a really long way.

Dr. Bradley:
Excellent. There's a great book I've read called Eat This, Don't Eat That, and when I think about the story with endometriosis, I would have to sort of put it in the endometriosis journey. So do what, and don’t do what. What would you say?

Casey Joe:
Do what, and don't do what. Okay.

Dr. Bradley:
For doctors.

Casey Joe:
For doctors. Do what? Listen to your patient. We know our body better than anyone. Yes, you may have went to medical school; however, this is our body, and we live in it every day, so listen to our patients. And don't do what? Don't tell us that it's just in our heads because 9 times out of 10, it’s not in our heads.

Dr. Bradley:
Excellent. Well, I want to thank you for sharing your journey. It's powerful. I think you've given us some very salient points to share and for doctors to have that wake-up call, that eureka moment. And I'm hoping that the next patient I see next week, I'll take part of your journey with me and open doors so that patient can feel better.

Casey Joe:
Thank you, Dr. Bradley. Appreciate it.

Dr. Bradley:
Thank you. And keep doing what you're doing. You're doing such a powerful job, and knowledge is power.

Casey Joe:
Thank you. I will, I will.

Dr. Bradley:
Thank you. Thank you.

Melissa, we've just had a great interview with Casey Joe. What do you think?

Dr. Simon:
Casey Jo, thank you so much for sharing that story. It breaks my heart every time I hear stories such as yours because, you know, at the end of the day, we really do have to listen to our patients. You know your body better than anyone else. You've lived in it, just like you said so articulately. And I have not lived in your body, and it's really important for us as healthcare providers to truly listen to the patient.

Dr. Bradley:
Melissa, thank you for taking part in this episode.

Dr. Simon:
Thank you. It was my pleasure.

Dr. Bradley:
Well, this discussion has provided some interesting considerations with respect to the impact of racial and ethnic biases when managing endometriosis. Unfortunately, our time is up. Thanks for watching and listening.

Announcer:
You have been listening to CME on ReachMD. This activity is provided by Omnia Education and is part of our MinuteCE curriculum.

To receive your free CME credit, or to download this activity, go to ReachMD.com/Omnia. Thank you for listening.