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Early Diagnosis: Its Pivotal Role in Optimizing Outcomes in Patients With Endometriosis – Psychosocial and Physical Consequences

Announcer:

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

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Dr. Shulman:

This is CME on ReachMD, and I'm Dr. Lee Schulman. Here with me today is Dr. Linda Bradley from the Cleveland Clinic in Cleveland, Ohio. We are also fortunate to have a guest with us today, Miss Samantha Denäe, who is a patient advocate who herself has unfortunately suffered through the issues associated with endometriosis.

Welcome to you both.

Dr. Bradley:

Thank you.

Samantha:

Thank you for having me.

Dr. Shulman:

It's great for us to have you here, so let's get started. Linda, let's begin with what are the physical and psychological consequences of a delayed diagnosis of endometriosis?

Dr. Bradley:

A delayed diagnosis should never happen, but it does. A delayed diagnosis means that a patient doesn't feel her story was heard, she wasn't listened to, and she has not been treated. Sadly, many patients suffer anywhere from 7 to 11 years without being heard, without being evaluated appropriately, and also, not having treatment. Seven to 11 years, that's devastating.

We wouldn't let that happen to a cancer patient. Also, patients see many physicians, multiple physicians, all types of healthcare providers, from nurse practitioners to physicians and allied health professionals. Also, they suffer. Relationships, sexuality. So, clearly, we realized that endometriosis is an equal opportunity disease. It affects all women, but some women, more often than not, are not heard. And so during this time, pain, disability, lack of success, and the delay in the diagnosis really can bring, also, psychological harm, anxiety, depression. Patients may feel withdrawn. They begin to think themselves, are they neurotic? And so friendships suffer, relationships suffer, and patients feel left out. They're not included in the discussion, and they go from doctor to doctor to doctor, basically being written off. And these are terrible things to happen to a patient.

Dr. Shulman:

You know, in a sense, you're describing a situation very similar to PTSD. you've been suffering through pain, you've been suffering through the concept that you're going crazy because you've seen all these doctors, some of them specialists, and they're telling you that

you don't have a problem, or you have a problem and it's not the one that you have.

Dr. Bradley:

So as a physician, we must recognize all the bullet points, all the small things, ask those questions, and then, most importantly, interpret what the patient is saying and making sure you understand what she said.

Dr. Shulman:

Linda, that's a great overview, but we're really fortunate to have somebody who has, unfortunately, lived through all of the issues that we've just discussed. So I'd like to introduce Samantha Denae and ask you, Samantha, to give us your overview of what you've gone through and hopefully what's happening in your life now.

Dr. Bradley:

Samantha, it's so great to meet you. I've heard so much about you. But I'd also like to know more about your journey. It's an intimate journey. Please feel free to share with us what you're comfortable with. How did the journey start? What kinds of pathways you went through and where are you now?

Samantha:

Well, thank you for having me. It's an honor to be here, to speak with you today about my endometriosis journey. So I was diagnosed with endometriosis in 2014, took years of getting a diagnosis. I have always had a debilitating period. My period has always been about 7 to 8 days. Having to miss school at least once a week and not being able to keep down like, water, food, it's just always been extremely debilitating. And when I was diagnosed in 2014, I also had ovarian cysts with my diagnosis. I, unfortunately, almost overdosed on codeine and that was kind of how I first heard the term of endometriosis. Thankfully, a doctor heard my symptoms, especially when it came to having a debilitating period, not being able to use the bathroom, it was very difficult for me. It took years to finally hear the word endometriosis, and once I did, I was told that I was going to have to have a laparoscopic procedure in order to find out if it's really endometriosis. I had 2 ovarian cysts that were both the same size as oranges that were also the same size as my uterus, and I've never been pregnant or had children before, so that was abnormal for my uterus to be so enlarged. And I was diagnosed with stage 1 endometriosis.

From there it was a whirlwind. It went from trying to figure out which kinds of treatments were going to work best for me, different birth control treatments I've tried. I've tried the Lupron Depot treatment. It was horrible. I will say the side effects are "woo," I can't even begin to describe. But found the Lupron Depot and then trying other birth control treatments, progesterone treatments to try to regulate my hormones. Nothing seems to have been working for me. My periods went from 7 days to 90 days for 9 months out of the year for 4 years. I was having faint spells. Anytime I would go anywhere I would feel like I'm going to pass out. I wasn't able to keep food down a lot, so I lost a lot of weight. I used to be like 40 pounds heavier than this, and so I lost that weight in about 4 months because everything that I ate, even water, I would just – I couldn't keep it down for anything.

My doctors, they couldn't really figure out how to make my periods sort of become regulated. That's always been a really big issue for me is how to have a regulated period. And so, because we couldn't figure that out, I thought about different options, you know, like a hysterectomy.

I thought about an ablation. I was told that when you have an ablation, you know, it'll help for the moment, but years later, your period is going to come back. So I felt like for me that was kind of counterproductive for me not to do. I had 3 hysterectomies scheduled. At that point, I was ready to just kind of ready to give up because I was having a period basically all year and for years. And I wasn't even 30 yet, had never been pregnant, had never had that experience of trying to figure out, you know, what's it going to be like to have children when you're diagnosed with endometriosis? That's kind of the first thing that they tell you is your fertility has been cut in half. And to hear that your fertility has been cut in half at such a young age, and you don't really know how you're supposed to maneuver from that outside of they just give you birth control pills, and that's kind of counterproductive, too, for me to take birth control pills.

And so from 10 years I've been dealing with endometriosis, and it started off very, very rocky. And it got even rockier. And from there, I will say being a patient advocate and educators sort of helped me to be able to kind of figure out how to manage the symptoms for myself and kind of figure out what kind of treatments would best work for me, because the birth control was – I felt like my body didn't really want to agree with what it was doing for me, and that's why my periods maybe were lasting so long. We kind of never figured it out, why I was having periods for such a long length of time. It's just really been – it was really hard, I will say.

Dr. Bradley:

So let me ask you. Women see so many healthcare providers. I'm just curious if you could tabulate or just tell me what type of doctors did you see? Specialists or primary care types of doctors.

Samantha:

So I started with a primary care, and then she sent me to an ob-gyn. For a while, I had the same ob-gyn. Kind of tried different birth controls just to see in high school if it could get regulated. It wasn't working for me. And I just was really only seeing just different ob-gyns. And once I started to get really sick, before I knew it was endometriosis, I saw, like, an endocrinologist, a urologist. None of them suggested endometriosis. But what I believe is that endometriosis is a full-body disease, and instead of just looking at it reproductively, the whole body will tell you; if you listen to all of the symptoms, it'll kind of tell you. You can kind of piece it together to maybe think that it's endometriosis.

Dr. Bradley:

Right, I agree. You said over a 10-year journey. When you left the doctor's office, did you feel heard? Did you feel listened to?

Samantha:

In the beginning, bamboozled.

Dr. Bradley:

What opened the door for you, do you think, that finally you found someone to do something or to listen differently?

Samantha:

I think a big part of it was I had to listen to myself.

Dr. Bradley:

Tell me more about that.

Samantha:

I walked past the mirror and I looked at myself, and I did not recognize who I was. I didn't look the same. It was like I was a totally different person. And I don't know if you ever, you know, look at yourself in the mirror kind of have, I call them come-to-Jesus meetings. I have to have them with myself sometimes just to give myself a pep talk. And so I looked at myself in the mirror and I said, Sam, I can't go out like this. I'm just going to be frank. I can't allow something to just make me give up on life. At this point, I was going to give up on life. I'm not even 30.

Dr. Bradley:

It's so painful for me to hear that.

Samantha:

Yeah, I don't have children. I've never been married. My relationship is falling to pieces, and I was just ready to – because at this point, this is all I am.

Dr. Bradley:

Right. So what happened and how did you get to the next part of that journey?

Samantha:

I started doing a lot of research and trying to –

Dr. Bradley:

On your own?

Samantha:

Yes, not even just about endometriosis, but people that I could find with endometriosis and people who look like me who have endometriosis.

Dr. Bradley:

People – women of color? Black women, okay.

Samantha:

Yes, yes, and –

Dr. Bradley:

So where did you find that?

Samantha:

I did not.

Dr. Bardley:

Okay.

Samantha:

The first thing I found was a Facebook group called Nancy's Nook.

Dr. Bradley:

Yes.

Samantha:

Nancy, yes, if you have endometriosis, you know about Nancy's Nook. But on Nancy's Nook, there are a lot of older women in their 40s and 50s who they have just found out that they have endometriosis, and I'm 25. So we have a connection because we have endometriosis, but we're not in the same age range. And these women are just now finding out they can't reproduce, and it's because they have endometriosis. And here I am, in the childbearing age, and I'm finding out that I have endometriosis, which has completely made me feel like I've been stripped of my womanhood because, naturally, now I cannot conceive. And so I didn't find any women of color, African American women, who had endometriosis on Nancy's Nook. I did a lot more research on Google trying to find people, could not find anyone, and I said, well, if I can't find anyone who looks like me, maybe I'm supposed to be the person who speaks out about endometriosis so that people can know about it at least. At least have heard the term, because nobody had ever heard of the word endometriosis before until – a lot of people that I know said they had never heard of it until I started to speak out about it. And then they meet other people, and they referred them to me to say, do you have endometriosis? Or it sounds like you may, like, go and check out Samantha and see –

Dr. Bradley:

What's going on.

Samantha:

Yeah, and see. And you could talk to her. And so me having that meeting in the mirror to tell myself I can't allow something like this to just pull me down, and not being able to find anyone who looks like me with endometriosis, that gave me the push that I needed. And honestly, I know a lot of people will say that endometriosis, you know, it's a detrimental condition to live with. It's not the best. It's not the prettiest. It's not the most fun. But for me, I will say it's a blessing because I've been able to help other people to know what it's like, to know the symptoms, and to be able to feel comfortable in talking about it, because we don't like to talk about our reproductive journeys. It's very taboo.

Dr. Bradley:

Before we close, I'd just like to know how are you doing now?

Samantha:

I am doing amazing, I will say. I don't have flare-ups throughout the month like most patients, like I used to. I had so many flare-ups, feeling like I was getting stabbed in my pelvic area, but I don't – I changed my diet and I think that's helped a lot. I've tried my best to cut out a lot of foods that causes inflammation, and I think that's what's really helped when it comes to keeping my flare-ups down throughout the month. My periods are normal now, no longer 90 days, 9 months out of the year; it's very normal. I sleep a lot during that time, which I have forced myself to do, to give myself dedicated rest because I do a lot throughout the other weeks of the month, so that one week is my time to just give my body a break.

Dr. Bradley:

Well, I think I definitely heard your story. You were very eloquent in describing this, it almost brings tears. And I think your journey is an important journey. And, again, as we've heard, many women have it, and endometriosis is an equal opportunity disease. And as your own journey has shown, sometimes certain ethnic and racial groups are highlighted, but I think the teaching moment is it's equal opportunity. We have to listen and learn.

I've learned a lot. I want to make sure that I leave you just a few seconds to give us maybe 2 or 3 bullet points that you want us, as physicians, to know and to take with us as we go to our offices next week.

Samantha:

First thing I will say is, when you have a patient and she is giving you a list of her symptoms, I would advise to ask 3 questions. Do you have a debilitating period every month? Do you have issues with going to the bathroom, and do you have painful sex? A lot of times, those are kind of the correlations to maybe you have endometriosis. Another symptom that a lot of us don't recognize is that we have foot cramps. And I know that's going to be kind of funny to hear, but most women who have endometriosis during their periods, either

the onset or during, we get cramping in that area, and so that's a big telltale sign, I think, of having endometriosis. And just remembering that it's a full-body condition, not just specifically to the reproductive system. So you have to look at the whole evaluation. And encourage your patients to really tell you everything that's going on, because sometimes we don't tell you everything. And I know you, as physicians, you all kind of know that, but encourage them. I think maybe we don't feel as vulnerable or comfortable enough to share, so I think in using the touch, because I think a physical touch shows you all as empathetic, and a lot of times people are afraid of physicians. A lot of times it's because they feel that you-all lack empathy. And so I think a touch just on the shoulder, of the hand just lets you know that you feel we're human and that we're not hypochondriacs, because a lot of times that's kind of what we get reduced to is hypochondriacs and we're just in here making it up.

Dr. Bradley:

Right, right.

Samantha:

So that's my advice.

Dr. Bradley:

Well, Samantha, you're an educator, you're knowledgeable, and as many people have said, keep causing good trouble. I wish you the continued health and happiness that you have. And just a pleasure to have met you.

Samantha:

Thank you.

Dr. Shulman:

Samantha, first of all, I'm just happy that you are finally at a place that you're happy with, and we spoke about that earlier, that so often we as clinicians fail to truly ask where do you want to be? And it sounds like that's, for very good reasons, now where you are. I think your story is so critical for our listeners and for clinicians who take care of women, because you highlight what I consider the double whammy of endometriosis. Your story highlights the delays, the doubts that you had that perhaps your clinicians had about what was going on. But your story also highlights that even after the diagnosis was made, and even after appropriate therapeutic options were offered, you still weren't necessarily getting better. And so it highlights the challenges that clinicians have in getting to that diagnosis, but also, even after you get to that diagnosis, also that not only does one size not fit all, but one therapeutic intervention doesn't necessarily get everybody to where they want to be. So I'm just really thrilled that you are where you want to be.

Samantha:

Thank you.

Dr. Shulman:

That is all the time we had. It's been a wonderful discussion with both of you. Thank you both. Thanks also to our audience for listening and have a great day.

Announcer:

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