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## The Impact of Early Diagnosis in Improving Patient Outcomes in Endometriosis: Physical and Psychosocial Consequences

**Announcer:**
Welcome to CME on ReachMD. This activity, titled “The Impact of Early Diagnosis in Improving Patient Outcomes in Endometriosis: Physical and Psychosocial Consequences” is provided by Omnia Education.

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**Dr. Shulman:**
Endometriosis is often called a public health crisis for women. Today, we’ll be joining a discussion with Dr. Linda Bradley and Dr. Suzie As-Sanie in which they will be evaluating the quality of life impact of endometriosis on women and how diagnostic delay leads to poor psychosocial and physical outcomes for these patients.

This is CME on ReachMD, and I’m Dr. Lee Shulman. First, I’d like to welcome Dr. Bradley to our discussion today. Welcome, Linda.

**Dr. Bradley:**
Thanks, Lee. It’s so great to be here.

**Dr. Shulman:**
In addition, joining us from her home in Michigan, I’d like to welcome Dr. Suzie As-Sanie. Hi, Suzie.

**Dr. As-Sanie:**
Thank you, Lee. It's nice to be joining you and Linda.

**Dr. Shulman:**
Fantastic. Let’s start our discussion.

Suzie, can you tell us why endometriosis is considered a public health crisis for women?

**Dr. As-Sanie:**
Sure, Lee. Health crises generally have significant impacts on the community and its population. And this definition clearly fits the impact of endometriosis on women and, often, their families. So we estimate about 10% or possibly higher of reproductive-age women are affected by endometriosis. And one of the major contributions to this crisis is the very long delay between the onset of symptoms and the diagnosis of endometriosis, which is anywhere between 7 to 11 years from when a person first begins to develop symptoms and when their condition is actually diagnosed. And so during this delay, patients often deal with many physical as well as psychosocial issues that negatively impact their life. They deal with these symptoms often on a daily basis, and these symptoms are often worse during menstruation until their condition is diagnosed and managed appropriately with treatment.

In addition, Lee and Linda, let me also briefly highlight some of the major symptoms associated with endometriosis. So the pathognomonic symptoms of endometriosis are pelvic pain, and they can be any combination of the 3 most common pelvic pain symptoms, which are pain with menses, which is called dysmenorrhea; non-menstrual pelvic pain or pelvic pain that's not specifically associated with menses; as well as dyspareunia, which is pain with vaginal intercourse. But these aren't the only symptoms that patients with endometriosis experience. Other symptoms can include pain with urination, which is dysuria, pain with defecation, which is dyskinesia. And when patients live with chronic pain for long periods of time, they often also experience many additional symptoms such as depression and anxiety, feelings of powerlessness, guilt, as well as other symptoms that really decrease their quality of life. Another not uncommon symptom of endometriosis or at least condition with endometriosis is infertility or decreased ability to get pregnant. Patients also find that many of these symptoms affect their relationships. So loss of intimacy, loss of work productivity, as well as a general impact on their family.

**Dr. Bradley:**
Thank you, Suzie, for this robust discussion.

Lee, did you know that upwards to 10% or higher of reproductive-age women often needlessly suffer the ravages associated with undiagnosed or incorrectly diagnosed endometriosis and often unnecessarily undergo treatments for their endometriosis?

**Dr. Shulman:**
Well, I think that fact bespeaks an issue that is unique to endometriosis but also found throughout healthcare. And that is with the real challenges of making a proper diagnosis of endometriosis and exacting a treatment that is going to be successful for that woman, if we place challenges in front of that, with delayed diagnosis or incorrect diagnosis, the impact truly is going to make for not just a problem for that 10% but an even greater percentage. And for me, it clearly states that there is a need for a call for action in addressing these issues, both the racial disparities as well as the overall issues with diagnosis and treatment of endometriosis.

**Dr. Bradley:**
Thank you, Lee.

And I'd like to introduce you to our endometriosis educator and influencer, Samantha Denäe from Atlanta. Samantha, thank you for joining us today.

**Samantha:**
Thank you. It's lovely to be here with you all today.

**Dr. Bradley:**
Samantha, we know that endometriosis-related symptoms can be very debilitating. Could you please describe your endometriosis-associated symptoms and how they've affected the different aspects of your life?

**Samantha:**
So I have dealt with a lot of symptoms with endometriosis, dysmenorrhea and debilitating and heavy periods being one of the major symptoms for me, as well as having difficulty with using the bathroom. And that means urination and bowel movements. I've had issues with both. Rectal bleeding has been a really big issue and was one of the signs to let me know that something was pretty wrong with my period and with my body, as well as brain fog. Brain fog is a really big symptom that I often kind of go through throughout the month, just kind of being able to figure out just the haze in the mind and just being able to figure out and focus on the things that I need to focus on a lot of times throughout the month. As well as headaches, dizzy and faint spells. I used to have faint spells a lot and would always have to take off certain articles of clothing just because my body temperature will always raise so high, so I would always feel like I'm going to faint and pass out whenever I would be out in public places. I had gotten to the point where I would carry an endometriosis card, and so that way if I was out and I passed out, someone would know kind of what was going on if I passed out and they would see blood kind of going down my leg, they would know, you know, kind of not to panic or maybe think that it's something else. Just so if I were to have to go to the hospital or somebody had to call an ambulance for me, they kind of had an idea of what's going on.

**Dr. Bradley:**
That's an amazing journey, amazing poignant story, and I think as physicians, if I were to sort of summarize what I hear from you, that when we look at endometriosis, there are many different buckets, many different silos. So, pain – and I'm just echoing back to you some of the things that I heard you say, and maybe I'll add a statement or two about things that I have seen as a physician.

So the pain aspect is one, and then we'll talk about the psychosocial. So the pain aspects – your dysmenorrhea, your cramping, your abdominal pain; dysuria, painful urination, and even sometimes blood in the urine, although you did not have that; dyschezia, painful bowel movements, sometimes those butt cramps that you talked about; headaches; brain fog; pelvic pain during periods, after periods, before periods. So it sounds like you have a lot of different things that we list in our textbooks for pain, and I've added a few others.

When we look at the psychosocial pains – you so commonly note these things, and thank you for your honesty, because some patients don’t recognize it. But again, the issue of depression; the issue of anxiety; sometimes sleep disorders, insomnia or early awakening, difficulty falling asleep; not feeling well; loss of self-worth, that you’re not available to your family and community; infertility, difficulty to get pregnant or stay pregnant; intimacy – we don’t talk about sexuality enough in healthcare, even though we’re speaking about a gynecologic topic. But painful intercourse, avoiding intercourse, hesitancy, lack of pleasure. Just personal relationships may suffer. Financial, the costs of pads, the costs of Diva cups, the costs of tampons. And so when we look at – broadly, as a physician, thank you for letting us listen to your story, and you really do highlight many of the tragic journeys that patients have to undergo for a long time. And I think your words really bring a sense of what pain is like, more importantly, how it affected you and what this journey has been.

So, Samantha, you discussed these symptoms with your physician, it sounds like.

**Samantha:**
Mm-hmm. Mm-hmm.

**Dr. Bradley:**
What did they say? How did they respond?

**Samantha:**
Not the best, I will say. Most times – oftentimes, just with pain medication or maybe a different birth control option to see if it will, you know, kind of provide me a little bit of relief. Most times it did not, and most times, the pain medication wasn’t working for me either as well. And so they weren’t really, I guess, forthcoming, I guess you can say, with trying to offer me other treatment methods or maybe other different kinds of ways that they could think of to kind of alleviate the symptoms that I was going through.

**Dr. Bradley:**
Thank you so much. So, Samantha, I want to put you in a big coliseum.

**Samantha:**
Okay.

**Dr. Bradley:**
A big place where you have thousands of physicians and you’re able to speak with your microphone. What would you tell them that could improve their management of patients with endometriosis symptoms? What would you shout to the mountaintops?

**Samantha:**
So if I were in a coliseum full of physicians, I would tell them that endometriosis is not a one-size-fit-all, and because it’s a whole-body disease versus just reproductive, you have to really listen to your patients and their symptoms. Because endometriosis can spread throughout the body, it can attach to any of the organs and cause the organs to attach to each other. Someone may have exasperated symptoms when it is the onset of their period versus when it’s not, and that’s important. Those are important things to know so that way you can kind of start to connect the dots on maybe it’s endometriosis instead of just bypassing that it’s endometriosis altogether. I feel like a lot of times, endometriosis just isn’t mentioned altogether. It’s like it doesn’t even exist. When you can start to kind of connect those symptoms with what a patient is going through, I think that’ll really help for endometriosis to stand out in a physician’s mind, like, maybe this is what’s going on, instead of just automatically going to something else and something that’s more common or what they’re used to seeing.

**Dr. Bradley:**
So thanks so much for giving us this sage advice and the wisdom that you bring to this conversation.

**Samantha:**
Thank you.

**Dr. Bradley:**
Again, I’d like to ask Dr. As-Sanie, do you have anything that you’d like to add to this conversation?

**Dr. As-Sanie:**
Samantha, thank you so much for sharing your experience. I know it's been incredibly frustrating and a very long journey for you as well as many other patients, but this is incredibly helpful and important for other patients to know that they're not alone. But it also really educates us as providers as to the personal experience and trauma that many patients face as they go through this difficult journey.

I also want to thank you for sharing your experience because not only does it educate us, but voices like yours are really the turning point for how we've come to recognize the importance as well as the impact of endometriosis, both raising its awareness for us to be better educated as providers, but also raising awareness to increase the funding for research to better understand and treat this really complicated and life-impacting condition.

**Dr. Shulman:**
Suzie, thank you so much. And, Samantha, thank you so much for being here today and sharing your personal experiences with us.

**Samantha:**
Thank you. I enjoyed my time here with you all.

**Dr. Shulman:**
For those just tuning in, you're listening to ReachMD. I'm Dr. Lee Shulman, and today we're joining a discussion with Dr. Suzie As-Sanie and Dr. Linda Bradley. They are just about to delve further into the importance of an early endometriosis diagnosis and optimizing patients' quality of life outcomes.

Suzie, with that as a background, why is there such a long delay in diagnosing endometriosis?

**Dr. As-Sanie:**
Well, I could say if we knew the reason for diagnostic delay in endometriosis, we would've solved the problem by now. But unfortunately, that's not correct. We've actually known for quite some time why the delay exists and it's multifactorial. So as early as 2006, Ballard and colleagues published an article in Fertility and Sterility that pointed out that there are many patient-related factors related to the delay in diagnosis of endometriosis. And some of these include patients' perspective that pain and heavy bleeding is normal and it's what they should expect with their period. So the lack of knowledge that having very painful and/or heavy periods could be a sign of an underlying disease was not known. We also know that patients often consider pain and bleeding to be a familial trait, that it runs in the family. All of my family members have periods that are painful and heavy, and so this should be normal. For some patients they've reported that admitting that their periods were painful and/or heavy was a sign of weakness or just that it was unlucky for them. And so these are certainly some of the patient-related factors.

**Dr. Shulman:**
Well, clearly, Suzie, there are pathophysiological issues that lead to this delay, but what are the physician-related delays?

**Dr. As-Sanie:**
Lee, that's an excellent point. I really want to emphasize that this is not just a lack of patient awareness, but there are many physician-related factors that also lead to the long delays in the appropriate diagnosis and management of endometriosis. So there's clearly a very important lack of knowledge as well as training in the diagnosis and recognition of endometriosis-related symptoms by healthcare providers, making this diagnosis very challenging to make. Physicians and healthcare providers often have a poor index of suspicion. And it's a complicated condition to often diagnose because the symptoms of endometriosis are often nonspecific and can also be common symptoms for other conditions. So upon referral, though, patients often are faced by similar challenges with additional healthcare providers due to the lack of knowledge as well as potentially lack of access to well-trained physicians in this condition.

**Dr. Shulman:**
Well, has anything changed since 2006?

**Dr. As-Sanie:**
Well, that's a great question and Simpson and colleagues evaluated 27 publications spanning from 2003 through 2020. And what they found, unfortunately, was that physicians and patient knowledge gaps, normalization of symptoms, low referral, and poor index of suspicion for endometriosis as a diagnosis still remains as a key deficit. So this means we know what the problems are, and we have for some time, we just haven't successfully identified and implemented strategies to fix this inherent delay in diagnosing endometriosis.

So this is a great reason and great measure as to why me and others are participating in this EndoVOICE initiative to raise awareness for both healthcare providers as well as patients regarding the proper diagnosis as well as treatment options for patients who suffer from endometriosis.

**Dr. Shulman:**
Suzie, thank you so much.

Linda, looking at the diagnostic delay, how do we begin to address this, considering our prior efforts have truly been less than successful?

**Dr. Bradley:**
So, again, I think we've heard from our patient. We have to listen, we have to act, we have to examine the patient, and we have to trust what they're telling us. So I think the diagnostic delay has been that we don't listen and we don't connect the dots, as has been said

before. So once we hear about all the pain, I think another important factor is asking the patient how many providers have they seen. When I ask that question and someone says I'm the seventh person, I have to think it's something that's different, that's out of the box, that they've not been treated for. And, again, as we've seen, 50 million-plus women – 10% or more of women. So it kind of makes it easy if you're the second, third, fourth, or the tenth physician. Think about the diagnosis and then do the exam, do the imaging, and the additional testing. But don't just write the patient off. That way, we will prevent the patient from cycling through the healthcare industry or healthcare hospital systems.

**Dr. Shulman:**
Linda, thank you.

Suzie, what is your view on how to address diagnostic delay for endometriosis in your clinical practice?

**Dr. As-Sanie:**
Thank you, Lee. And I think all of Linda's points were excellent. Really listening to patients and having a very low threshold for the clinical diagnosis of endometriosis and then moving very quickly to treatment interventions that are centered on patients' individual goals and preferences at that time, I think, is one of the most important parts. I mean, we also need to recognize that patients' symptoms can change over time. And their goals can change over time, and so really working with your patients on a regular basis to reassess their symptoms and monitor their symptoms is incredibly important.

**Dr. Shulman:**
Suzie, thank you.

Unfortunately, that's all the time we have today so, again, I want to thank all of you for joining us here today, for listening in. I want to thank Suzie As-Sanie for being here with us from your home today.

**Dr. As-Sanie:**
Lee and Linda, thank you so much. It was great to be part of this podcast today.

**Dr. Shulman:**
And Linda, thank you again for being here and really adding your valuable insights into this discussion, into this very important discussion about identifying the delays in diagnosis and treatment and trying to mitigate those issues.

**Dr. Bradley:**
I thank you again for this invitation and a great, lively discussion. Thank you.

**Announcer:**
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