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ReachMD

www.reachmd.com

info@reachmd.com

(866) 423-7849

Endometriosis: A Patient's Journey Through Diagnosis and Beyond

Announcer:

Welcome to CME on ReachMD. The following activity, *Endometriosis: A Patient's Journey Through Diagnosis and Beyond*, is provided in partnership with Omnia Education and supported by an independent educational grant from AbbVie.

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Here's your host, Dr. Andrea Singer.

Dr. Singer:

As the third leading cause of gynecologic hospitalization, endometriosis affects about 10% of all women and 30% to 50% of symptomatic premenopausal women. This number is probably higher, however, because some women are asymptomatic, and while the diagnosis of endometriosis is primarily clinical,

it is far too often overlooked in primary care, which can delay diagnosis of several years.

I'm Dr. Andrea Singer, and in this activity, we will cover the various aspects of endometriosis including its symptoms, common comorbidities, and how patient education and shared decision-making can impact diagnosis and treatment. Joining me in this discussion are Dr. Stephen Cohen and Sarah. Dr. Cohen is faculty at SUNY Upstate Medical School and Albany Medical Center. His patient Sarah has been diagnosed with endometriosis and is here today to share her experience.

Dr. Cohen and Sarah, welcome to the program.

Dr. Cohen:
Thank you.

Sarah:
Thank you for having me.

Dr. Singer:
So, Sarah, let's start with an overview of your journey so far. Can you tell us what symptoms you had and what led to your diagnosis of endometriosis?

Sarah:
So, my journey started in my early teens. I started my menses at 11, and ever since then it has been very hard, hard and sharp pains. I started birth control when I was 16 to help to ease the pain, and that got me through for a few years. And then, around 2010—I was the age of 21—I started getting pain so bad that I couldn't leave my bed. After many ultrasounds and tests, she diagnosed me with PCOS and said I was obese, that I needed to lose weight, which was extremely hard because I had no energy and I was physically in pain. It was hard to work out, but I persevered, and I lost over 80 pounds and I still had the pain.

After years of suffering, she then sent me to a specialist, a surgeon specialist in our area. And then, in July of 2012—I was 23—I had my first laparoscopic D&C, and I was diagnosed with endometriosis. After that, he started me on a combination of progesterone and continuous birth control pills, and it worked for a couple of years, but then the pain started to come back and it came back worse. When I came back, he wound up performing another laparoscopic D&C, and that was in July of 2017. I did have a Mirena in, and I asked for it to be removed as the Mirena was not improving my pain at all, and it kind of—as weird as it sounds, I “felt” that it was there, so I asked him to remove it, and I was still in pain after the laparoscopic D&C. We started using the Depo shots to try to help control the pain. And although it did lessen the pain, I felt more depressed than I had ever been before.

I met with Dr. Cohen shortly after that, and for the first time I felt like a doctor actually listened to me. He genuinely cared about what I was saying and sympathized with me when I explained all the pain that I felt. I've always talked about a hysterectomy before with other doctors, and every doctor I've ever spoken to said I was too young, and when I said it to Dr. Cohen, he was the first doctor that said, "Not necessarily," which made me feel like I was being heard for the first time by any doctor.

So, as you can understand, when the symptoms started was when I first started experiencing my depression. I was put on many psychotropic drugs, but it's so hard when you feel like a doctor isn't listening to you and you're begging for someone to listen. The depression just got worse.

Dr. Singer:

Well, that gives me a nice lead-in to be able to ask him some questions, and thank you for sharing that story with us. And I will come back in a moment to some of what you said. I want to talk a little bit more about the pain and the impact on your everyday life, but before we do that, I just want to pick up on a couple of things you said, because this was a long process with seeing many different clinicians over a number of years, as you've talked about, and spoken also about not necessarily feeling as though you were heard and certainly other complicating issues needing to distinguish what was actually causing the pain and look at the gastrointestinal system as well.

So, Dr. Cohen, can you comment on what Sara just described, and do you think this is the typical patient experience for someone with endometriosis?

Dr. Cohen:

I actually do think it is the typical experience, unfortunately. I'm not casting blame at anybody. It's a very complicated disease. It affects not just the physical patient but the mentality of the patient, the mentality of the family, the structure of the family, so it's way beyond what we usually treat in GYN, a simple ovarian cyst or a little abnormal bleeding. A patient in pain all the time is predictably going to have depression, appropriate depression. And then, some of the secondary effects, possible irritable bowel, like in this case, when you're depressed and things aren't going right, those symptoms seem to occur even more, or at least they're perceived more because it's just one more thing you have to put up with. We have this push-pull with these patients where I would love to treat this patient, I would love to make her feel better—that's why I went into medicine—but I'm sort of out of things to do, and so we have 2 frustrated people. We have a frustrated provider and a frustrated patient, and it becomes a very difficult, complex issue. And on top of that, in today's medicine, we all know it's kind of drive-thru medicine. And typically this is not a patient that can be seen quickly. This is a patient you have to listen to, empathize with, and then find out what she wants done and what her priorities are and then work

with her.

Dr. Singer:

Turning back to you, Sarah, for a moment, you mentioned pain before, and certainly significant pain. Can you tell us a little bit more the impact that this had on your everyday life?

Sarah:

Absolutely. So, pain has impacted my life since I first started my menstrual cycle. I can remember it very vividly as a very sharp, debilitating pain. I was lucky that my mother was diagnosed with endometriosis, so she understood and kind of saw the signs beforehand, so she was a big help with that. Pain became second nature to me, though. I recently quit my part-time job as a bartender because the physical demand was too much to take with this terrible pain that I'm experiencing. It is very painful to have intercourse, which is a part of everyday life to some people. It's been over 2 years, and it's very painful, and I bleed a lot, so it's very difficult to lead a normal life.

Dr. Singer:

So, pain clearly can be impactful and really affect how we function. Dr. Cohen, can you expand on what, perhaps, the causes of the pain are and briefly tell us about the potential etiologies of endometriosis?

Dr. Cohen:

We know what it looks like histologically. We know the lining of the uterus, the endometrium, is outside the uterus, and histologically it looks the same as the endometrium in the uterus, but they behave very differently, and we're just starting in this decade to learn much more about the behavior of the endometrial glands themselves. So, although they look like the same tissue, they don't behave the same way. We also know that one of the common ways of getting endometriosis in your abdomen is reflux out to the fallopian tubes, and we've known that for a long time. Most women reflux endometrium up through their fallopian tubes, and 90% of women don't have endometriosis, so there's something unique about the patient that develops endometriosis. Maybe it's genetics. Sarah mentioned that her mother had endometriosis. Maybe there's a gene that allows that endometrium to implant, where in other patients it's rejected. We're learning about the proteins and secretion factors that endometriosis secretes. So, it's not the endometriosis that's causing the pain. It's what it does in the abdominal cavity that causes the pain. And there are many things, some of which are COX-2 inhibitors and other COX-2s, hormones, and other things that create the pain. So, endometriosis is secreting all sorts of stuff into Sarah's abdomen which is making her hurt, and we're doing a lot of research on how we can stop—if we don't take away the endometriosis, how we can stop it from secreting these hormones or block those hormones or proteins from causing inflammatory pain.

Dr. Singer:

Sarah also mentioned depression earlier. Do you find, Dr. Cohen, that this is common in patients with endometriosis? How do you address depression when managing your patients?

Dr. Cohen:

Certainly, most of our patients with chronic pelvic pain from endometriosis or any other cause are depressed. Most offices now do depression screening. Many of our patients, if we listen to them, or we just look at them, we know they're depressed. So, a combination of medical therapy and listening to the patient and supporting the patient, and also, as you're going to address a little later, the ability to let the patient plot her course.

Dr. Singer:

For those just tuning in, this is CME on ReachMD. I'm Dr. Andrea Singer, and I'm speaking with Dr. Stephen Cohen and his patient Sarah on the topic of endometriosis.

Turning to management, Sarah, once you had a diagnosis of endometriosis, how were you managed? Are there other strategies that were used that you'd like to mention?

Sarah:

I feel like the hormones, all hormones that I take me feel very sick and lethargic, and I feel that the hormones also affect the depression. Immediately when I got the Depo shot, like I said, I spiraled into a depression, and I think that had a lot to do with it. There's been a lot of medical management with medications and IUDs and surgeries and anything like that.

Dr. Singer:

Dr. Cohen, Sarah is now your patient. Can you share how her management plan has been established, how the 2 of you have worked together and what you've come up with?

Dr. Cohen:

Well, Sarah and I are very early in our relationship here, but we take a real good history, we listen to what the patient's saying, we're finding out we should prioritize what her priorities are, what's most important to her, which pain is the worst, what she would like treated, and then we put that all together and we try to pick something that we think might work. And Sarah, like most patients, has some comorbidities—maybe some IBS, maybe not, and other things going on. Was she depressed before her pain, or is the depression a result of her pain? What came first, the chicken or the egg? The most important thing is not what's necessarily going to work, but that we get a plan that we both think is good, and we go on that plan. And then, like anything else in life, you can change the plan. But we'll work together, and at least that makes both of us feel more comfortable that we're working in the same

direction.

Dr. Singer:

Can you briefly talk about perhaps a couple of other options from a medical standpoint that either Sarah wasn't on or that weren't mentioned, one of which has been sort of a mainstay of therapy in terms of GnRH agonists and now the newer GnRH antagonist that has been approved, and just briefly mention how those work?

Dr. Cohen:

All right. Well, the GnRH agonist has been out for a number of years, probably close to 20 years, and both drugs end up doing the same thing but on totally different pathways. The GnRH agonist basically down-regulates the pituitary so that you give enough drug, you overstimulate, you drain it, basically—in lay terms you sort of drain it—and then the estrogen level drops because of that. The antagonist is more specific, it blocks the receptor. So, it looks entirely different even though the end of it is a reduction in estrogen. The other significant difference in these 2 drugs is elagolix is dose-related. The more you give, the lower the estrogen level goes. So, you have some regulation of how low we're going to drop the estrogen. And we may be able to control some of Sarah's depression by not dropping it as low as Lupron did, which is not dosed.

Dr. Singer:

Sarah mentioned her long journey from symptom onset to diagnosis and her frustrations with feeling unheard. Are there resources for patients like Sarah to help them feel empowered throughout the process and to help them educate themselves?

Dr. Cohen:

Yes, there are certainly some very good resources. For example, the Endometriosis Foundation of America has been doing this for a long time, and now with the internet and others, they're able to get their word out to patients that they couldn't do in the past. ACOG, the American College of OB/GYN, has patient resources. ASRM, American Society of Reproductive Medicine, has sources.

Dr. Singer:

Before wrapping up this discussion, Sarah, I would love to hear any final thoughts that you have or that you'd like to share with our learners.

Sarah:

Absolutely. I'd like to add to what Dr. Cohen said. Educating yourself is the biggest thing. when you educate yourself, the more you know, the more you can advocate for yourself

Dr. Singer:

I think that's terrific. Empowering our patients, helping them to find information, and then hopefully as providers, being aware of the need for shared decision-making and open discussions really can move the needle in the direction that we would like it to go. Any last thoughts, Dr. Cohen?

Dr. Cohen:

I think Sarah's a role model for a patient who really understands this disease. Patients that don't have an understanding, that we don't give time to explain things to, think that we, as physicians, don't care. Sarah can decide, ultimately, whether invasive surgery is necessary and she is willing to undergo that to have a life that is relatively pain-free and not live her entire life not being able to do the things she wants. That's her decision, and I'll be happy to support her.

Dr. Singer:

This discussion has given us some great patient and physician insights into the diagnosis and treatment of endometriosis. To access some of the patient education resources that were mentioned, including several different pamphlets, they can be found on the Related Content section of the landing page.

Dr. Cohen and Sarah, thank you both for sharing your expertise and experience with our audience.

Sarah:

Thank you for having me.

Dr. Cohen:

Thank you.

Announcer:

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Thank you for listening.