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https://reachmd.com/programs/cme/endovoice-live-endometriosisa-chronic-burden-of-reproductive-years/37176/

Released: 10/22/2025
Valid until: 10/22/2026
Time needed to complete: 60 minutes

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ENDOVOICE Live: Endometriosis—A Chronic Burden of Reproductive Years

Announcer:
Welcome to CE on ReachMD. This activity, titled “ENDOVOICE Live: Endometriosis - A Chronic Burden of Reproductive Years” and supported by Sumitomo Pharma America, Inc.

This replay of a live CME broadcast offers practical strategies for earlier diagnosis, equitable care, and medical management of endometriosis—enhanced by valuable insights from a patient advocate.

Dr. Madueke-Laveaux:
Hi everybody. That was an amazing lecture, and we're really excited to spend the next hour discussing endometriosis, a chronic burden of reproductive years for many of the women we take care of. So let's get started.

Here are some disclosures.

And so this next hour, we're going to do four main things. Our goal is to discuss the importance of early diagnosis of endometriosis and how that can change the lives of the women we take care of. We're going to discuss patient-centered diagnostic and evaluation tools, the importance of shared decision-making strategies, and patient-centered treatment. And then we'll introduce and discuss the risks, benefits, limitations of the GnRH antagonists in the medical management of endometriosis. So let's get along for the ride. Okay?

All right, so I'm going to start with discussing the cost of delay. To lay a framework for this, let's discuss the prevalence of endometriosis. 6% to 10% of reproductive-age women have endometriosis currently in the United States, and globally up to 10% to 11%. The average age at diagnosis is 28, and 6 of 10 women with endometriosis are undiagnosed. What's also important to note is that up to 50% of women with subfertility and 90% of women with chronic pelvic pain also likely have endometriosis. So this is a really big deal for women.

The average delay in diagnosis is up to 10 years, and the longer the delays, it is linked with worsening pain severity, disease progression increases, surgical and medical complexity, and early recognition can truly alter disease trajectory. I have these images here to really just highlight how challenging this disease can be when it comes to even surgical treatment.

So what are some of the barriers? Why is it taking so long to diagnose endometriosis? So this is a systematic review, and it's quite sobering. It's qualitative, and so in this review, you hear the voices of women who have struggled with finding someone who hears them when they describe their pain. I won't go through each of these, but I'll highlight a couple.

This patient, the first one, says, “I was experiencing a lot of pain on penetration during intercourse. I went to the doctors, and they did an internal exam and said, *‘Look, everything is perfectly normal,’* and suggested that it might be psychological and I am just anxious.”

Another woman describes how she grew up watching her mother receive pain injections every month, and so when she started to have pain, she just assumed that was normal.

Another patient said, “My doctors didn't even know what endometriosis was. I had to explain my diagnosis, explain the treatment. How can I trust them to help me when I need help.”

This is the real-life experience of women with endometriosis.

So here's a summary. What is the issue? So women start to manage their symptoms, mostly, then compounded by the fact that their symptoms are normalized, so they think, “Well, maybe I just take more ibuprofen and I'll be fine.” People are dismissed by their providers. There's misdiagnosis, and we'll talk a little bit about some of the comorbid conditions that can confound the diagnosis of endometriosis. And there truly is insufficient knowledge, not only by some of our primary care providers, but even by non-specialist gynecologists. I know during my residency, we read about endometriosis, and it's like, okay, we kind of cognitively understand, but until you truly understand what the woman is going through and rethink what endometriosis is like in a living woman, it's really hard to understand the gravity of early diagnosis.

So what are some of the comorbid conditions that can really make it challenging to pinpoint endometriosis exists? GI comorbidities. So if you think about the way the body is built, the pelvis is not separated from the abdominal cavity, right? There's an inflammatory process undergoing in the pelvis, but it affects the entire GI system. So a lot of women with endometriosis will have irritable bowel syndrome. They may have just even overlapping symptoms of bloating, constipation, abdominal pain, and this fuels misdiagnosis—up to 3.5 increased risk of IBS in our endometriosis patients. They also sometimes will have inflammatory bowel disease, and this is really, really, really challenging, because they do share inflammatory pathways—the two diagnoses—and so this can confound issues.

Bladder pain. So I can't tell you the number of women who have been treated time and time again for UTIs that don't exist. They're just in pain because there's inflammation in their pelvis. And then there's this chronic overlapping pain phenotype in women, and we'll talk a little bit about this cycle of pain that starts with this long life of living with pain.

So what tends to happen with these comorbid conditions is that when a woman comes in with pain to her primary care and they talk about the gastrointestinal symptoms, they're sent to the GI doctor who evaluates and says, “Well, you don't have IBS.” And so the patient is again confounded by her symptoms and thinks she might be crazy.

So what's going on here? The pain cycle, it's really, really challenging, because the woman has lived her life in pain. It's disrupted her work and school. Many women will tell you that from the time they started having their menses, they could not go to school one week out of the month. It reduces physical functioning and mobility. There's strain on intimate relationships as they get older, and sometimes fertility issues arise.

So you're living with the pain, and then there's anxiety surrounding the pain. What is it doing to your mental health? And physically, what is it doing to you? The brain becomes more focused on the problem, as our bodies are conditioned to do. Changes take place in the nervous system. Then there's more pain, and there's more anxiety, and then you have more changes.

And so this cycle of pain looks this way: the woman will initially say, “Well, my pain used to be confined to my period, but now I don't have a pain-free day,” and so that's what chronic pelvic pain is. And so it is so debilitating.

In this study, what they did is they compared the quality of life in women who were coming in for just a sterilization laparoscopic procedure, and then they compared that to controls who had pelvic pain but didn't have endometriosis, and then women who had pelvic pain and endometriosis. And as you see here, the dark purple indicates the quality of life of women with pain and endometriosis was significantly lower than the other control groups.

The psychosocial burden of delay. So we talked about this life lived in pain and then dismissed and then normalized. And so the patients are anxious and depressed. They feel invalidated and frustrated. This social withdrawal, reduced participation, and they're dealing with this financial stress of having to figure out what's going on with them, sometimes seeking care outside of insurance coverage.

So what can we do to change this paradigm? Early clinical recognition is key. And why is it key? Because historically, traditionally, surgery has been thought of as the only way to diagnose endometriosis, and we'll talk a little bit more about why that's not always required.

So this was a call to action that I really, really enjoyed reading, because here, the authors challenge us to think about endometriosis as a menstrual cycle-dependent, chronic, inflammatory, systemic disease that often presents as pelvic pain. So if we reframe in our minds what endometriosis is, maybe we can give it a chance for clinical diagnosis.

So how do we do this? Careful history-taking. Most of the time the patient will describe painful periods, debilitating. “Ibuprofen kind of works, but I have to triple, quadruple my dosing.” When they're sexually active, they may describe deep dyspareunia, painful intercourse with deep penetration, cyclical dyschezia. So they're having bowel movements—it's usually okay—but once the period comes, forget about it. They're grasping at anything before they can have a bowel movement. They have dysuria that is not indicative of any type of infection.

And sometimes, when the endometriosis goes beyond the pelvis, and I'll show some pictures, they'll talk about having pain underneath their rib cage and sometimes even collapsing of lungs during their menses. This is all endometriosis.

So you can imagine a patient has these symptoms, and I'm like, “Well, I'm not sure you have endometriosis. Let's go to the OR.” No, I know you do, right? Because you have all the symptoms that indicate that there is something going on, and I'm not going to delay your diagnosis and thus your treatment.

So we get a history. There's a focused gynecologic exam. If you do a pelvic exam, and usually with trained hands, you can sometimes feel nodularity and some changes in the patient who has endometriosis. However, oftentimes, if you don't know what you're looking for, patients just leave the clinic saying, “Oh, your exam is normal. I didn't see anything going on.” And that's not always true.

There's a role for noninvasive imaging, and we'll touch on that briefly in this first portion of our hour. Ultrasound and MRI has evolved over time, and we're able to find some pathognomonic findings that can surely indicate the presence of endometriosis. And there we can start empirical treatment without immediate laparoscopy.

So here, now what I don't want you to take from this talk is that there is no role for surgery, because there is, in fact, a role for surgery in the treatment of endometriosis. What we're saying is that the need for surgery should not delay diagnosis and treatment. So these patients are our patients who have been on medication for some time and now they're refractory to treatment, so you need to debulk. So I think of endometriosis surgically as sometimes you need chemotherapy first, and then you need a debulking, and then you go back on chemotherapy. It's not a cancer, thank God, but some oncologists will argue with you that it's worse than a cancer surgery, and that's why we don't want to take surgery lightly when it comes to endometriosis.

Sometimes endometriosis involves the rectum, and so when we rush to the operating room and start to do these aggressive dissections, the patient's quality of life can diminish significantly, and that's why patient-centered care is key, acknowledging that quality of life is a priority and determining with the patient what their fertility goals are. So laparoscopy, still traditional, is considered the gold standard, but it's not always required. Early diagnosis can be made with clinical evaluation, radiologic findings, and we can decrease this delay in diagnosis and improve timely care.

Here is an MRI image here to the right. To the left for you is kind of a graphical exam illustration of this area of spiculation. I don't know if I can point, but right behind the cervix and just close to the rectum is where endometriosis often lives when there's deeply infiltrating disease, and we can see that on MRI. So once I see that, I know what we're dealing with. It not only helps us think about the potential of surgery but lets us start treatment immediately.

There's now augmented pelvic ultrasounds that can help to identify any changes in the soft tissue that can indicate endometriosis. This becomes really critical, because oftentimes, not only are patients told there's nothing wrong on exam, nothing is going on with you, but then the ultrasound shows nothing at all. So this is something we want to avoid by implementing augmented pelvic ultrasounds. And if you don't have it where you are, most centers of excellence will have started offering augmented pelvic ultrasound to identify endometriosis in imaging.

So what are key takeaways? Diagnostic delay averages nearly a decade, and each one of us in this room can play a pivotal role in decreasing the time to diagnosis of endometriosis. Delay worsens physical and psychosocial outcomes. Earlier recognition equals better quality of life. And although there is a role for laparoscopy, a time and a place, it is not always required for diagnosis.

Dr. Bradley:
Okay, thank you. What a great segue into what we need to know—the who, what, when, where, and why we do different things for endometriosis. So I'm going to speak with you about GnRH therapy. And I think this is an exciting time as a gynecologist, to see women, to look at what's happened really since 2018, and more importantly, in 2022 with new medications on the horizon—oral medications that can be used for women.

For many of us—I'm just going to quickly go through—we've lived with oral contraceptives, progestin therapy, whether it's oral, subQ, or IM. The GnRH agonists, which are intramuscular. But the interesting, novel, new are oral medications that we can use—the GnRH antagonists that we'll speak about. Also the progestin IUDs, and less commonly, but aromatase inhibitors. So I think this is stay tuned, listen and learn, and it's exciting to be able to offer women new opportunities.

So when we look at the menstrual cycle, we know that in the normal situation from the hypothalamus, there's pulsatile release of chemicals that lead to LH and FSH activation, which then leads to the menstrual cycle, estrogen, progestin. What we now have for the GnRH antagonists, what we are doing is targeting GnRH receptors in order to reduce estrogen-driven endometriosis.

So how does it work? It's oral. It's reversible. They bind competitively to the pituitary gland and GnRH receptors, thereby preventing receptor activation of the endogenous GnRH. So very quickly—rapid suppression of LH and FSH, and then we have a plummeting of our estrogen and progestin hormones, therefore leading to hypoestrogenic state, and absence of menstrual cycles or amenorrhea. So basically it's targeting GnRH receptors and then blocks everything downstream.

So there have been several studies, and so we're going to first look at the daily relugolix. There's been several trials called the SPIRIT trials, almost involving about 1,260 women—1,300 women, who have been followed up to 24 months. And there are also some extension trials. And what was done? They used a GnRH antagonist called relugolix, 40 mg, and it's one tablet that's taken that also has estradiol 1 mg and norethindrone acetate 0.5 mg, and also had an arm of the placebo. And they're looking at patients' quality of life, their pain score, things that endometriosis may affect. So we have a group of women who took the combination therapy and those who did not.

It is mentioned 24 months, and there are some extension trials which show continued improvement and safety. And the primary endpoints—as Sandra talked about, women complain of the pain, poor quality of life. And then, as she mentioned, there's this noncyclical pain—pain when it's not during a woman's menstrual cycles. And they compared all of that to placebo. They found safety. They found tolerability with the medication.

And what did we find? The relugolix CT—means the continuous medication—improvement in cramps, the non-menstrual pelvic pain for cramping or dysmenorrhea—75% of women achieve reduction with the relugolix, compared to only 27% of women on placebo. Also, the non-menstrual pelvic pain also improved, 59%–66% compared to the placebo.

And when we see the patients and we will follow them and ask them questions, the outcomes are reduced problems with having intercourse or painful intercourse. Many of these women have been on opioids or high doses of NSAIDs. As you mentioned, some of my patients tell me they take Motrin like 800 mg, eight times a day. And I have had a patient with liver failure, so they can't—even though it's over the counter, and they double up or triple up, it's not good. So we find with the relugolix, improvement in pain and less opioid use.

All the things that women look for, quality of life, mood, work, school, habits, family—much improvement. And these are the things that we're going to ask our patients about as we look at the therapeutic choices and how they do over the time that we're following them. They can do things every day, enjoy their family, their hobbies, be able to just relax without pain, and overall, they feel better and they function more fully.

There are side effects from hypoestrogenic states, but usually pretty tolerated. But just to mention, as you can see here, sometimes headaches, the hot flashes seen in this patient population taking the relugolix.

So again, as I mentioned, the trial was for 24 weeks, and then women could stay on it all the way up to about 104 weeks. And what I liked about this is that it continues to show improvement.

The main problem are menstrual cramps. Also, the noncyclical pain is also 75% improvement, and again, improvement in their ability to have intercourse.

And the most important thing is we as physicians, sometimes we look at things and look at the statistics and say, oh, it's statistically improved. But really, when patients are asked, they really have marked improvement in their symptoms. And we all have learned about the problems with drug use and overdosing and getting started on opioids. We found that 91% of patients were opioid-free, compared to 60% at baseline, and 75% no pain medications at all, up from only 7% of women at baseline. So this is an important quality of life and metric that I think we have to look at.

So how do we decide? And as Sandra said, it used to be when I was a resident, everybody got surgery to make a diagnosis of endometriosis. And so what I like now is that we have room for patient scheduling. We have room for patients to talk to us a little bit more, to find out really what they're looking for, to see what their contraceptive needs are. So let's just sort of look at patient selection. Sandra will go through the times where you really have to do surgery, but I'm going to stick with some things that you might do before.

So obviously, this is for women in their reproductive years. We do know that women in the menopause—potentially very low percentage of women who start on hormone therapy with endometriosis will have recurrence of symptoms. I just want to make sure you're not using this for pain in someone that's clearly menopausal.

We talk about the new ways of confirming a diagnosis—they could have had a laparoscopy, they could have had an MRI, they could have had a specialized ultrasound, and you want to make sure that there's no contraindications to hypoestrogenic state, or that they want children, especially for the relugolix combination therapy. This is not a contraceptive pill. Okay? So patients would have to use another method of contraception. But again, patients with pain and they're age-appropriate.

And the symptoms—moderate to severe pain, dyspareunia, impact on quality of life. What are they missing? And we know that we still sometimes start with a combined hormonal contraception or progestin, because some women need it for birth control. Again, this is not a birth control pill, but we might have a patient that's been on birth control or Depo-Provera or progestin, medroxyprogesterone, norethindrone, but they have progression of disease. You may want to then switch to a GnRH antagonist.

And then it's important, because this is a hypoestrogenic state, even with add-back therapy, you want to make sure someone has not been anorexic for years, prolonged amenorrhea, really, really thin, because of the potential concerns for bone health and potential risk for osteoporosis. We recommend for all women who are going to go on therapy that they're getting adequate calcium, either through diet or through over-the-counter calcium supplementation, 1,200 mg a day, and vitamin D 800-1000—especially in Cleveland, we definitely don't get enough vitamin D. So I have my patients to supplement.

And then sometimes, how else might you and the audience consider starting the medication? Well, for some that you may be considering making a referral to a surgeon—and our surgeons are booking out 4, 6, 9 months sometimes—that you really have a high index of suspicion, they failed other therapies, the birth control pills, can't take it or progestin, you might want to strongly consider a GnRH antagonist. We sometimes use this for ovarian suppression, for fertility preservations, and to medically optimize very, very significant symptoms. These medicines work really quickly in patients. We're usually seeing—I've seen it within 2 to 4 weeks. This is not something that's usually going to take 6 months before they get better.

Let's see. For preoperative consideration, some surgeons will recommend oral GnRH antagonists 2 to 3 months preoperatively. As we do the surgery—endometriosis, sometimes with these dense adhesions that you saw with the pictures—it can be bloody, decreased vascularity, improves our dissection planes when we're really trying to peel off or do excisional surgery on the peritoneal structures. And also, patients have deep infiltrating endometriosis, and that's when the endometriosis goes more than 5 mm into the bowel, to the bladder, to vital structures, and sometimes also in the treatment of endometriomas. So these are preoperative considerations that a surgeon might make.

And then we have patients who may want to get pregnant, and we would consider a GnRH antagonist when there's bilateral ovarian involvement or low AMH, usually less than 1.2, and there's a thought—because of less oxidative stress, less cytokines and inflammatory cells—that this will help preserve follicular function. We really don't have great knowledge about this, but theoretically, we feel that this might be a mechanism of action for the GnRH antagonist to work.

Also, again, those severe symptoms, as Sandra described, the patient holding on for dear life to have a bowel movement, bladder—some patients really have urgency, frequency, even sometimes erosion of endometriosis, where they get frank hematuria due to the deeply infiltrating endometriosis. And sometimes we will use this for oral therapy for 3 to 6 months. Works quickly. You can speak with your surgeon.

The big thing, and I think you're going to mention this with the next topic—it is so important that when you send your patients to a doctor that does endometriosis surgery, that you have a collaborative practice. Yes, we're excellent physicians, but we also work with colorectal surgeons, our urologists. It's a medical management, sometimes pelvic floor physical therapist; it's not just the surgery, depending on where this deeply infiltrative endometriosis goes or is. I walked in the OR the other week, and I'm looking and I said, I think that's a lung. They're up by the—drop the lung in order to get endometriosis for this patient who did come in almost every other month with a pneumothorax. But it wasn't a GYN surgeon doing that surgery, we work in with others—a cardiothoracic surgeon. So again, there may be reasons to be on this, even if you're going to refer patients for surgery.

Postoperatively, we do the best surgery that we can, but there may just be in an area where it's just too tough or too unsafe to get at that we made add therapy afterwards for incomplete resection. And some surgeons, with stage 3, stage 4 disease, may put patients on, within a month, therapy to prevent reoccurrence.

So the incomplete resection—where would it be? Near the ureter, major blood vessels. Do your rectovaginal exam—you sometimes will feel nodularity. Sometimes that's very difficult. And we also have to be patient-centric. There are some patients that might rarely need to end up with a temporary colostomy, ileostomy, and there are going to be patients who say, “Under no circumstance, Doctor,” even if you're working with colorectal, “do I want to have either bag,” so to speak, “even if it's temporary.” That might be a patient for me or our team where you would add adjunctive therapy. And again, this is to suppress the residual tissue and prevent rapid progression.

And I think I said this already—prevention of recurrence. And I think this is important—25% up to 40%–50% of patients, even in the best of hands for surgery, endometriosis can really reoccur, so we can't even say with cutting it out that it's going to cure. Sort of like fibroids—you can take out 20 this year, and 5 years later there's another 20. So again, there's things that we can do.

So these are the current pharmacologic options. I'm not going to go over the ones that we know about, but basically we've talked about mechanism of action for the GnRH antagonists. There's two products: elagolix and there's also relugolix. Elagolix does not have the add-back therapy with it. There's two different doses, which we can see here. There's a twice-a-day dose of a higher elagolix of 200 mg, but that's limited therapy for 6 months. Many of us are using the relugolix, a GnRH antagonist, because it has the add-back—both estrogen, progestin—which allows us to use it for longer with less potential side effects, the vasomotor, vaginal dryness symptoms. And so, again, this was approved in 2022, a lot of interest in our community in using this.

Again, we talked about we have to talk to the patient. I'm very good for saying the woman at the end of the speculum is who we're caring for. It's important that we speak to her, know beforehand what bothers her, what symptoms does she want to get better? And so sort of looking at the quality of life—her mental health, physical health, daily function, sexuality—that's kind of that profile. Your pain score from 0 to 10 with the happy face and not happy face. See your patients. Some of these patients, we just do a lot of virtual visits at 3, 6, and 12 months. But talk to them at least in 3 months so that the patient has a sense that they're connected to you. And then she might come back at 6 months, and you may do these interval in-office or virtual visits if things are going better. Let them be able to contact you in the office. They do not want to feel abandoned—listening and learning what their symptoms are. What else might you add from our toolbox in order to treat them? And then you document your treatment response.

Things that you can follow. You won't want it to become a hypoestrogenic state, so a serum estradiol levels of less than 30 or FSH, LH. Especially relugolix, it doesn't have a lot of impact on the liver function, but you may want to monitor that, include lipid profile, bone density recommended but not required. And you may want to do, if you're only using a non-add-back regimen, after 3 to 6 months you would have to go off-label to add a norethindrone and estradiol. And again, the exercise, calcium, and vitamin D.

If someone now wants to get pregnant, you should stop 3 to 6 months before so that the hypothalamic-pituitary axis can function again, your folic acid. And then you have to look at, long-term, their symptoms. Pelvic exams every 6 months for the first 6 months, for about 2 years.

Dr. Madueke-Laveaux:
Thank you so much. That was really fantastic and a nice segue. And you really alluded to a lot of things we'll talk about in this next section, which is really rethinking the role of surgery and endometriosis diagnosis, and also kind of, where does it fall in line when you're thinking about a patient-centered approach?

So let's talk about laparoscopy a little bit. So the traditional mindset, like we talked about, most of our training, you think about surgery as first line is the default option. The perception is that laparoscopy is essential for a diagnosis and treatment. I don't know if it's necessarily just a perception, but this is what we were taught. This is what we knew. And a lot of the groundwork laid for endometriosis occurred before we had these medications. So we do need to adjust to the advancement that we're making in medicine, and that should affect the way that we manage pathology.

So the first moment you go into the operating room, it opens the door for more repeated procedures in a woman's lifetime. So you have to be very thoughtful about that first exposure to surgery, and it's not always aligned with patient goals.

So this is a trial. It was a review—systematic review in 2020 looking at clinical trials involving over 1,500 women who had undergone either an ablation, excision, or just a diagnostic laparoscopy to visualize endometriosis. The quality of evidence across these clinical trials is about moderate to very low. The improvement of overall pain was uncertain across the 14 trials. What they did see was increased intrauterine pregnancy rates when there was an excision or ablation—not just looking and seeing the lesions. And there was no real difference between ablation versus excision at the time of surgery.

So the risk of repeat surgery is that, like I'd mentioned, once you have your first surgery, you're opening the door for more surgeries. Regardless of if you excise or ablate, the recurrence of symptoms is almost sure, especially if there's no suppression after the surgery.

Surgery is our happy place for surgeons, but it can also be some of the dreaded places you want to be. Because despite the fact that, in the best of hands and in a good center, we usually have excellent outcomes, it doesn't always work out that way. And the more complex the surgery is, the more challenging it can be not only for the patient, but also for the teams.

So adhesion formation is very real, and there are complications from that. So endometriosis, on its own, causes inflammation, which causes a lot of adhesions to form. Then you go into the OR and you cut, and what happens is, as healing occurs, there's even more adhesions. So you want to be thoughtful about the OR—not afraid of the OR but thoughtful about it, and then prepare. What an endometriosis patient does not need is someone who's so scared to go to the OR that they avoid it. So there's a fine balance. And so oftentimes, I'll tell my patients: Oh no, when it is time for surgery, you be sure I will take care of you, but it's not time yet—and there's something about that that is really consoling and reassuring to the patient.

Increased surgical complexity with each procedure and diminishing improvement in quality of life are some of the risks of repeated surgery.

So this, again, was a systematic review, it was just looking at many studies over time and looking at what happens surgically as far as outcomes in patients with endometriosis. Some patients improve significantly immediately, and some relapse quickly. Now, it's unclear whether or not the patient is in suppression after how good of an excision was performed. It doesn't really look into the details, but regardless, up to 40% of patients reported no improvement in pain after surgery. There's no universal guarantee of long-term relief.

Unfortunately, with a lot of these gynecologic conditions that we manage, they truly can be chronic. I mean, they are chronic diseases—fibroids, endometriosis. As long as you have a uterus and you have ovaries functioning, if you've proven that you have that pathology, you probably will always kind of have it. We just need to manage it and try to prevent it from occurring.

Fertility outcomes remain unpredictable, and this overall really highlights the need for individualized care planning in our patients. So medical first and multidisciplinary care is critical.

So I always describe to my patients who try to understand why they're in so much pain that the pelvic floor is a basket. So if you just put your hands back together, like this, this is the basket of the pelvic floor—all these muscles. And through that floor, you have the bladder, urethra, you have the uterus, you have the rectum, right? Any one of those organs that is in chronic pain, what happens over time is that the entire basket is triggered. You have muscles, you have nerves, you have all of these other organs surrounding the primary organ of pathology. And so that's why the pain is so severe, because inflammation doesn't just stay in one place.

So that's why you need multidisciplinary care. You need, sometimes, anti-inflammatories. You need pelvic floor therapy. You need muscle relaxants. You need to think about an anti-inflammatory lifestyle, diet. These things make a difference. So it's a combination of this multidisciplinary care that gets a woman to improve her quality of life and control her symptoms. So you can do all these things and really delay the need for surgery. I’m not saying there's never surgery, but you can delay the need.

And why do we delay it, and how does it make sense to delay it? If the woman's quality of life is preserved in the absence of surgery, then it is appropriate to do so. I hope that makes sense.

So now we're going to move on to Ms. Kornegay, and I look forward to hearing from you this morning.

Ms. Kornegay:
Thank you. Thank you. My name is Lauren Kornegay, and I'm the founder and executive director of Endo Black. We are a nonprofit that focuses on Black women living with and impacted by endometriosis—a nonprofit that is led by patients first.

I am from Oxon Hill, Maryland, who, for those who don't know, is about 10 minutes outside of Washington, DC, area. I was diagnosed with endometriosis on March 18, 2011. I consider myself to be a lived experience expert.

Though I was diagnosed in March of 2011, while I was in high school, I did deal with some horrendous pain, and it was not something that we talked about a lot in my household. But I was in so much pain that my mother would break up pieces of Percocet, put it in applesauce, so that I could actually go to school. We did not know that that was an issue. We just thought that that was something that was a part of life.

And as you see, I was 22 in college and preparing for my midterm when I ended up bleeding through my H&M dress. And I pointed out H&M because I loved H&M at the time, but this was my speech class. I was actually preparing to actually do a presentation, and this was a repeated cycle. I had no idea that my cycle was going to be reoccurring.

I ended up going to the doctor's office. They told me to go to my ob-gyn immediately. Doing this in college on my own was a difficult process, so I had to find my new ob-gyn. I found a doctor off Hartford Road in Baltimore, Maryland. It was a family practice. I had the opportunity to go there. She asked me how were my menstrual cycles? I said, My left knee hurts when my period comes on. My right knee hurts when it goes off. I have pain in my chest. I have pain in my back. And she said, “None of that is normal.” She then did a pelvic exam, and she was able to see that I had a reverted uterus. And at that moment, she said, “You may have endometriosis.” So that was when I went ahead and I got my diagnosis through surgery—a laparoscopic surgery in March of the following year.

5 months later, however, I ended up having an emergency surgery, leaving about 2 gallons of blood in my abdomen. What I thought I was doing was trying to be healthier. I knew that I had endometriosis, and I wanted to make the right decisions. But when I decided to run around my neighborhood, I actually caused friction, and it caused the cyst to rupture. Not knowing that, I just thought I was completely out of shape and that I had issues with breathing heavy. I decided to get in the shower, but things started to get dark in the shower. I said, well, let me go lay down. Before I can make it to my bed, I passed out on the floor. So I ended up going to the hospital with the help of one of my great friends, and she advocated for me. And at that moment, I knew something was wrong because of the severity of the situation and how they rushed me back.

But all in all, honestly speaking, you all seemed like it made you feel like it was terrifying, and in fact, it was. I felt very alone. As many people that were around me, my support system, no one knew what was going on with me. No one understood. This was not a part of the conversation that I had with my ob-gyn about what endometriosis meant. I did know that I had a benign cyst, but I did not know what that looked like moving forward. So my diagnosis was terrifying, and it was very confusing. And I hope that this conversation can help us get to a place where it's not as confusing and terrifying for other women.

Bias and dismissal in care—medical websites describe endometriosis as a white woman's disease. In 2020, I was approached by one of our community members telling me that a website did have white women as a risk factor for endometriosis. I turned to my friends and I said, “Well, what does she want me to do about that?” And they said, “You have the nonprofit.” And I said, “Oh, okay.” So we started to do research, and we found out that there were also five other hospitals that had that same information.

And that's no ill will or malicious for any of the medical providers, because they are not web designers. They are just medical providers. Those are two different entities at hospitals, which we do recognize. But we were able to communicate with those medical providers at those hospitals, and they did update their website immediately.

So I did not see myself in the data. I did not see myself in any of the resources or any of the language, or anything for that matter. That led me to create my own nonprofit. My mother always taught me, “If there's a void, you fill it. And if you're going to complain about something, you do it yourself.”

All right. So some of the messages that we have—one in particular is these aren't just gaps in care. There are gaps in respect, acknowledgement, and representation. We are people. We are not just numbers. And I know it is sometimes very, very difficult to see patients, and I’m glad to be in this position, because I do recognize that this is something that medical professionals cannot handle. You all cannot control the amount of time that you have with a patient, because it is required for about 10 to 15 minutes. For me, I understand that, but patients may not all understand that and know that, so it will be great for you all to just share that, because this is something that's required of you—for you to see as many patients in a day that you can.

From story to strategy, okay. You can be a part of that healing. Shared decision-making matters. Listening to your patients is very, very important, and trust is built when patients feel seen and believed. It does make a huge difference. It makes me feel comfortable to share more about what may be going on. A lot of times, patients may be coming in and not even recognizing that they're not sharing the symptoms that they need to share for you to get the diagnosis that you need to get. So the more comfortable you make them feel, the more they start to open up.

I had a really, really great ob-gyn when I lived in Columbia, South Carolina. She made me feel very comfortable. I kind of forgot that I was at the doctor. She made me feel so comfortable that I was able to share certain things with her that led to a better care treatment for me, and that we were able to get the answers that I needed.

Dr. Madueke-Laveaux:
Thank you, Ms. Kornegay, for sharing that. Excellent. Thank you. That was definitely deserved, because it takes a lot of vulnerability to share that story, but really important for us to see you and hear you and think about you when we speak to patients in pain.

So that patient-centered care planning, we talked a little bit about, and I won't belabor the point, but when it comes to surgery, because sometimes it does come to that, you really want to try to direct your patient to an endometriosis center or somewhere where you know that they will get thorough care. And then keep up with your patient. If you’re not a gynecologist or you're not in the space where you send them, to ask: Are you better? Did they listen? If not, come back. Let's re-strategize. Let me get you to where you need to go.

So when patients have this very complex pathology, it is our job to make sure that we have all the teams ready and available and familiar with the patient. I send MRIs to all my consulting doctors. I say, “This is what our strategy is. If and when we're ready for surgery, we need you to be available.” And I share that with the patient so they know that there are active plans ongoing for her support.

So again, patient-centered care planning, getting a team ready when the team is necessary, and having a point person for the patient to reach out to in times of distress and when they just need someone to encourage them and keep them going with advocating for themselves.

Dr. Bradley:
And I would also just add, if you went back by one slide—at our institution, because we're said to be extemporaneous here—but we also have, just like the cancer doctors have a tumor board, we do a monthly tumor board for endometriosis, with a phenomenal radiologist who plans with us or goes over the MRI images or if there's a really complex ultrasound. So I would also add we can read our own, but it's amazing what she picks up.

And then we are able to videotape our cases, and then maybe a week or two later, our residents will put together—because she's nosy and wants to see was she right. And it's so nice to go back and see the video and then see the MRI, so everybody learns to be better readers. So these centers are very, very important, so try to find one in your area.

So now is more of a discussion. We have a few minutes. And I think in terms of looking at disparities, one of the things I think working at the Cleveland Clinic, sometimes I get to be a hero, and I want all of you to be a hero also. When someone new comes to my office and presents with the pain and discomfort and has a compelling story, just remember the numbers from this conference—that it takes up to 4 to 7 years, multiple providers. I ask the patient: So how many other providers—nurses, physicians—have you seen? And if they tell me that they're number 5, a light bulb goes off. And I say, now I need to listen to this patient very differently, see what was done, but not pass her off as someone who's just difficult, pain-seeking behavior, or just a woman with many mental problems. I mean, sometimes that comes across—or very anxious.

So we wanted to just sort of challenge, as—and we're all going to fill in things, because we just want to pull everything together. Again, there was a myth when I was growing up that this was only a disease of Caucasian women. About 2 years ago, I published, with my fellows, a paper, because when I—I hate this now, because you get older—but when I was a resident at an inner-city hospital, under-resourced hospital, all the patients that were people of color—the black and brown women—came in and it was always PID, pelvic inflammatory disease. And our paper is on this. And I'll never forget being a chief resident, and the patient said to me, “Dr. Bradley, if you give me another shot”—what was it back in the day? Rocephin and whatever it was. And I really had to stop. And then she started to cry, and I said, “I'm going to really listen.” We took her to surgery in one of those frozen pelvises. I mean, you want to scream and call your attending—but again, anybody can have—this is an equal opportunity disease.

And so just remember that all women deserve the ability to be listened to and heard. And so we have—I’ll just go through this one—this whole issue, we are all biased. Okay. I'm biased as a person of color. We all have biases, right? But you have to remember how that's taught. We know in even studies with pediatric kids in Los Angeles, little kids are 8, 9, and 10 years old, come in with a broken leg, and just look at the same diagnosis. It could be the same leg. And kids that are Caucasian get more pain medicine. Kids that are brown and black go home with Tylenol. Okay? Objective, just following the patient's story.

So we have to remember, what are we doing for one group? Are we doing for the other? Think about that. And what would you do if a different person was sitting in front of you? I always say that because this is a CEO's wife, would I do anything different? Would I react different? Would I add a different imaging? A follow-up? Availability to contact me and to get a hold of me? Every woman's pain deserves belief.

And then, again, I think what we're all saying is we have to think about the young woman missing—if you're a school nurse, if you have friends, kids, or girls are missing school 1 or 2 days a month, or 5 days a month, that is not normal.

And so I think we have to—there could be many other diseases—but put it in your mind: adolescent dysmenorrhea, you think about Müllerian anomalies, things that aren't right in the developmental stage. We won't go through all of that, but you have to think about it.

Those who have pelvic pain or infertility, regardless of race and ethnicity—give everyone a chance to get the diagnosis. Think about the diagnosis, early treatment, and hopefully, rarely nowadays, surgery.

And I think we're going to go back and forth here. You’ve probably got one.

Ms. Kornegay:
So your pain is real and deserves investigation. Feeling validated and just recognizing my experience with my first interaction with a doctor was an amazing feeling to be heard. I never had that question. And I've, of course, been to doctors numerous times before, but to have that interaction as my first time as an adult who scheduled her own appointment, and having the ability to actually be seen by my doctor felt really, really great. Because just imagine if you have a college student who scheduled their own doctor's appointment, who was in pain, who had issues, and went to that doctor and that doctor dismissed them. That will probably be the last time that they did that ever. So just making sure you validate the symptoms immediately—don't question authenticity of it.

Dr. Madueke-Laveaux:
Endometriosis can affect women of all backgrounds. Actively dispel myths about who gets the disease. We talked about that in the previous slide.

The other thing that comes to my mind, and I had to catch myself—and as women, when you come into the doctor's office, you have your makeup on, you look good. You don't look like how you looked when you were in pain, crying the night before. And I had to remind myself of this, because sometimes I'm like, “But you look so happy.” And I had to just say, well, what would I do? I would look my best, right? You want to look good. So don't let the woman in front of you, who is doing her best to present herself as the strongest, most beautiful person, to distract you from helping her know that you're ready to hear her.

So even if we have 10–15 minutes, I'll say, “Well, we have 15 minutes, but the world is your oyster. I'm just kind of here, so let's go.” And just even breaking the ice and say, "Tell me, tell me what's going on." And if I don't have time, we'll make another appointment, and you can call me, and we can make a virtual visit—and all of a sudden they laugh and they like, "Okay, let me tell you what's happening."

But it is our job to envelope that woman in that moment and captivate and let her know that she's captivated our audience because she deserves it. And it makes a big difference in the rest of her day, in her life, really.

Dr. Bradley:
And for these next two, I would just say, yes, we've said to take concerns seriously, but we also have to remember—in medicine and in life—there are a lot of isms: I-S-M-S—classism, racism, homophobia, ethnic changes, obesity—all of these isms. And sometimes the woman that sits in front of you, if she's not polished, if she's from a different class, a different ethnic group, a different set of resources, we may fail to give her honor, to listen.

The most important thing, as Lauren has said, is for us to keep our mouth shut, let the patient talk. We interrupt within 30 seconds of most conversations. You have 10 minutes with the patient. I do the same thing. I just say, put my pen down. Well, now we have scribes that do our automated, with our computers and our phones. So that's very lucky. I think it's the best system now. I say, "I just want to listen to your story. Just tell"—and then I'll just do the uh-huh and tell me more, maybe a little sentence, "Describe that a little bit more for me." But try to let them have the full—whatever number of minutes—before you interrupt. The who, what, when? How does it affect you? When did it affect you? When did it start? What are you doing? So when you leave out of that room, you have a great opportunity to know how she's doing. What is her own pain score? Okay?

I think those are important—just sort of communication strategies—because if you listen, and what I learned in med school, 80% of what you need to know you learn from the patient's history, and your physical will add the other: that rectovaginal exam, the pelvic exam, the bimanual, and then a little bit, sometimes from the imaging

And so I think as we get ready to close here, quickly, I think there's a card on your table—just think about this. And I hope that—we all hope that next week, when you see a patient having symptoms that we talk about, that you'll make a commitment. Okay? Committing to implement three strategies: What will you do? What would you consider for someone coming in with pelvic pain, regardless of race? How is your communication and listening habits going to improve? And then how might you advocate for bias training? That can include the nurse that rooms the patient: "Oh, Dr. Bradley, she's here for pain." And it kind of starts off—I was like, well, if she came in with abdominal bloating and you thought she had ovarian cancer, we would be interested. Don't miss this diagnosis.

So just commit to being a better listener, a better questioner, a better resource person, and then make your team. I don't care if you're in the smallest community, wherever you are, we individually can make it happen. You can stoke the fire in your department about listening.

And what we're excited about are the new treatment parameters that have emerged in the last decades. We have the old—but sometimes, like marriage, what do you have to say? Something old, something new, something borrowed, something blue. We have new things now for treatment, and it's not our ancestors' treatment protocols.

Dr. Madueke-Laveaux:
This is difficult but necessary conversations in your workplace. Again, we just talked about this—implicit bias training, eliminating some of the preconceived notions we may have, and what literature has historically told us will be critical in this.

So this is a call to action. We're going to leave it on this slide just so you can refer to this as we move forward. Thank you so much for your time and attention.

Announcer:
You've been listening to a replay of a live broadcast offering practical strategies for earlier diagnosis, equitable care, and medical management of endometriosis—enhanced by valuable insights from a patient advocate. This activity was provided by Omnia Education and is supported by Sumitomo Pharma America, Inc.

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