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Patient-Centric Tools to Support Shared Decision-Making: Diagnosing and Assessing Endometriosis

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Dr. Shulman:
Evaluating patients for a suspected diagnosis of endometriosis can be more easily accomplished using validated questionnaires. Subsequently, shared decision-making can lead to more patient adherence to treatment and likely improve both short- and long-term outcomes. Today we will be joining a discussion between myself, Dr. Linda Bradley, and Dr. Melissa Simon, in which we will be addressing the validated diagnostic tools for endometriosis and strategies for achieving successful shared decision-making.

This is CME on ReachMD, and I'm Dr. Lee Shulman.

I'd like to welcome Dr. Linda Bradley from the Cleveland Clinic in Cleveland, Ohio.

Dr. Bradley:
Thank you, Lee. It's so great to be here.

Dr. Shulman:
And in addition, joining us from her home is Dr. Melissa Simon, my colleague from Northwestern Feinberg School of Medicine in Chicago.

Dr. Simon:
Thank you, Lee. It is nice to be joining you today, and Linda.

Dr. Shulman:
Great. Let's begin our discussion. Melissa, based on symptom presentation, many clinicians may have an insufficient index of suspicion for an endometriosis diagnosis. Are there any validated quality of life questionnaires available to help better assess the patient?

Dr. Simon:
So some things to consider would be Bourdel and colleagues publication in 2019 with regards to a systematic review they did of quality of life questionnaires for use in patients with suspected and diagnosed endometriosis. They looked at 201 studies in that publication from 1,538 published articles. And the most relevant quality of life questionnaire scales that they included in their evaluation in this publication were the SF-36. It's also called the Short Form-36. There also is a version of that short form questionnaire that is 12 questions instead of 36 questions; they're both relatively easy and quick to answer from a patient's perspective. There also is something called the EQ-5D, and that basically looks at quality of life in 5 dimensions. There's also the EHP-5 and the EHP-30, which is an endometriosis health profile.

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Dr. Shulman:
Melissa, that was great. From that short list of the most relevant questionnaires for endometriosis, did Bourdel and colleagues provide any specific guidance as to the best choice?

Dr. Simon:
Yes, actually, Lee, the SF-36 is one of the most frequently used generic scales in endometriosis. The EHP-30 is the most frequently used endometriosis-focused scale, and EHP-5 and EQ-5D also performed very well in that review.

Those scales were really the only ones to report a minimally clinical importance difference. So I think it's important to think about different screening tools that are relatively easy to implement in your own practice, given your own administrative and practice flow and your team members' comfort with administrating such questions.

Now from Bourdel et al, both the SF-36 and the EHP-30 scales appear well balanced in terms of strengths and weaknesses. They're both validated, reliable, precise, and sensitive. They are available in frequently spoken languages, which is really important, and easy to administer and complete. The EQ-5D and EHP-5 have also important strength points and the great quality to be short and really easy to use in daily clinical practice.

Dr. Shulman:
Linda, let's focus on the SF-36 and EHP-30, as they represent truly the 2 most widely used questionnaires. Can you discuss their strengths, weaknesses, and differences when applied to endometriosis?

Dr. Bradley:
Yes, I'm happy to do that. The SF-36 is a generic status measurement scale. It can help assess the health-related quality of life independent of the disease study. There are 36 questions, one relating to health transitions over time. It has been validated across many countries, so it represents a broad populational assessment.

36 also measures physical functioning, the role of limitations related to physical exam, bodily pain, general health perception, vitality, social functioning, and even limitations related to mental health. It's easy to use and score. It can be self-administered. It takes about 5 to 10 minutes to complete. Its strength in endometriosis is great because it is a best indicator of pain and its impact on the patient's health-related quality of life. The weakness: it's not just specific for endometriosis and it doesn't measure all the subset categories as it does for the EHP-30 scale.

Dr. Shulman:
Linda, that was a great overview of the SF-36. Can you tell us a little bit about the EHP-30 questionnaire?

Dr. Bradley:
I think folks will like the EHP-30. Why? Because it was specifically developed for endometriosis. And there's several categories, 5 of them. The issues of pain are evaluated, control and powerlessness, social support, emotional well-being, and self-image. The strengths? It's the most reliable and thoroughly validated scale for endometriosis. It measures unique quality of life aspects of endometriosis and scoring may be unaffected by where the patient is in her menstrual cycle. It is recommended by ASRM and ESHRE for the use in endometriosis. It's been validated across many countries, so it represents a broad populational assessment.

And finally, weaknesses. It does take about 5 to 10 minutes to complete. It provides subscale scores, but not an aggregate score.

Dr. Shulman:
Well, and I think, Linda, and I think you would agree, that it's really important to understand that no matter how good or not good a questionnaire is, they all have weaknesses. They're all going to miss something or not cover something as well as another. So it really, I think, behooves our listeners and our clinicians who are going to consider using them that they will have benefit, but not to sort of comprehend that the use of this will be the end-all of a diagnostic process. It is a part of the process. It will help identify certain women, but it will not be an entirely 100% guaranteed assessment for the diagnosis or lack of diagnosis of endometriosis.

Dr. Bradley:
Agree with you fully.

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 doctors Linda Bradley and Melissa Simon. They're just about to delve further into validated diagnostic tools and strategies for achieving shared decision-making when assessing and managing endometriosis.

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Melissa, I suspect that all of us are aware of the concept of shared decision-making, or SDM. and I believe that we adhere to SDM in our clinical practices as related to endometriosis. But do we actually adhere to that practice?

Dr. Simon:
Well, whether we do it or not is a matter of personal opinion, but we can all benefit, actually, by getting a bit deeper into the woods related to shared decision-making.

I'd like to introduce a publication by Cetera and colleagues in 2023 from the *International Journal of Women's Health*. It's called ***"SO FAR AWAY" How Doctors Can Contribute to Making Endometriosis Hell on Earth***. The article actually provides a listing of unintentional clinical practices that, if not addressed, can often lead to or worsen the distress associated with endometriosis. While termed a humanistic approach in the article, it provides food for thought on how to structure some of our SDM discussions with patients.

Dr. Shulman:
Melissa, I understand. And I actually have some familiarity with that publication. As you go through the clinical practices, can you please indicate which you find most useful in your clinical practice?

Dr. Simon:
Sure, Lee. The approach includes 8 dimensions that physicians need to address during the SDM discussion to help ensure patient buy-in, engagement, agreement with the therapeutic approach. This includes objectification or failing to incorporate patients' unique feelings and emotions. And then another dimension is passivity, which is the failure to encourage the patient to express self-empowerment with their decisions. A third dimension is homogenization, which is failure to treat the patient as an individual. And then the next dimension is isolation, which is failure to appreciate and address the patient's feelings of isolation. Loss of meaning is failure to appreciate and be empathetic to the patient's distress. Loss of personal journey is the failure to consider more than the patient's present. Another dimension is dislocation, which is failure to engender a sense of ease and confidence in your approach to the patient. And a final dimension is reductionism, which is focusing on symptoms and medical treatments or exams and results and not the whole patient themself.

So I really would like to have my colleagues consider these 8 dimensions when undertaking shared decision-making in their clinical practices, as they may further help the clinician and patient navigate this key interaction in this journey of endometriosis.

Dr. Shulman:
Melissa, that was a phenomenal overview of how we all should be incorporating shared decision-making into our care of patients. I can't thank you enough for that.

Dr. Simon:
You're most welcome, Lee.

Dr. Shulman:
Linda, I think this would actually now be a good time for us to discuss some of the ways that we empower our patients through shared decision-making. Or perhaps a unique approach to this process, because clearly there is a great need for us to make our opinions about the care that our patients are getting something that our patients can use for them to make ultimate decisions about how we approach diagnostics and therapeutics.

Dr. Bradley:
I think we finally got it right, this issue of shared decision-making. We are no longer dictators. We are no longer parents to our patients. The American College of Ob-Gyn has provided very good guidelines that Melissa just summarized, and I think we just have to take that to heart. Again, the basic idea is listening, letting the patient have a voice. Part of the concept, also, is to read body language, have empathy, give patients a range of options, be supportive. All of these things take precedence, and at the end, it's not a major decision that day, giving patients information, that they can always come back and we talk about more.

So shared decision-making is listening, advocating – I'm going to put that in there – and then responding to our patients' concerns. But we are not to dictate their care. We empower them and in so doing, they empower themselves.

Dr. Shulman:
You know, I think it's important for our listeners to understand that while we may have a much better understanding of the path of physiological processes that are going on, that doesn't necessarily put us in the most advantageous position to make the correct choices for that patient. So anytime we can add our expertise to the process, but adding the expertise, not taking the expertise and using that as a cudgel for patients to go a particular way with their diagnostic or therapeutic choices.

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Dr. Bradley:
Right. And I agree, especially with endometriosis. For the most part, it's not a life-or-death situation, and with a shared decision-making conversation in the office, we've shared discussions, we've educated, and it allows our patients to come back to us when they're ready to make the next move and to provide more information. So sharing that day doesn't mean a decision today, taking a prescription today, signing up for surgery today, but how I see shared decision-making in my office is information, listening, understanding, and the empathy that all of that embraces.

Dr. Shulman:
Empathy is absolutely critical.

In a similar fashion, Melissa, what are your thoughts about incorporation of SDM into your clinical practice and what you see with colleagues and how they incorporate SDM into their practice?

Dr. Simon:
I think SDM is super critical and standard of care to be incorporated into clinical practice. It's how we value our patients and how we start to engender trust, and it helps build that foundation for the care journey that a patient embarks on with their healthcare team for endometriosis treatment.

Dr. Shulman:
Melissa, thank you so much. I think the 3 of us all agree that we may take a different approach for empowering our patients, but ultimately it is our patients who need to make this decision based on the information we provide them, their understanding of their own personal health and well-being and lifestyle, and in that way, likely increase the probability that the course of action will be successful.

Unfortunately, that's all the time we have for this program today, so I want to thank our audience for listening. And thanks to Dr. Melissa Simon, as well as to Dr. Linda Bradley, for sharing their expertise and insight. It was great speaking to both of you today.

Dr. Bradley:
Thank you very much.

Dr. Simon:
Thank you so much, Linda and Lee. I really appreciated joining you today.

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