Managing Endometriosis Leading to Infertility

Endometriosis is a debilitating condition in which tissues similar to uterine tissue are found outside of the uterus, most often in the pelvic cavity and on surrounding organs, causing chronic pelvic pain, infertility, and many other symptoms. The relationship between endometriosis and infertility has been debated for many years. About 25% to 50% of infertile women have endometriosis, and 30% to 50% of women with endometriosis are infertile. Research shows that the natural capability to produce offspring (fecundity) is lower in women with endometriosis as compared to women without. In addition, endometriosis is associated with a lower live birth rate. We are talking to Dr Suneeta Senapti of University of Pennsylvania about the impact of endometriosis on women's fertility and how it can be managed better to reduce the burden of infertility.

Full Transcript:

Priya Menon: Good evening everyone, Welcome to Cure Talks. I am Priya Menon, your host. Today we are discussing how to manage endometriosis leading to infertility. The relationship between endometriosis and infertility has been debated for many years. And joining us today to understand the condition better is Dr Suneeta Senapati, Assistant Professor Obstetrics and Gynaecology from the Hospital of the University of Pennsylvania. The patient perspective will be discussed by the patient advocate panel comprising of patient advocates, Casey Berna, Heather Arnold Brown, Anna Lucia Krupp and Valerie Landis. Welcome to everyone to CureTalks. We will be addressing questions to the audience towards the end of the discussion. If you have a question for the panel or for the expert, you can send it in to priya@trialx.com or you can also post your question in the comments section.

Priya: So before we start with the discussion, I would like the panelists and our patient panel to introduce themselves and share their stories with us. We will start with Casey Berna.

Casey Berna: Thank you for having me. I am a social worker and also an endometriosis and infertility patient. Like many patients, it took me a long time to get diagnosed. But eventually I was able to get the care that I needed. So I started advocating in the community so that other patients wouldn't go through the challenges I went through for getting care.

Priya: Thank you Casey. Next we have Heather. Hi Heather!

Heather Arnold Brown: Hello! I am 23 yrs old and I was diagnosed with endometriosis in 2016 after a lot of unexplained pain, irregular cycles and everything. So I started a foundation called kNOw ENDO and its to bring awareness to the reality of endometriosis. I felt very alone when I was diagnosed with endo, not knowing what it was or what to expect. I am trying to bring awareness to endometriosis and that's what I can.

Priya: Thank you Heather. Anna, you want to go next?

Anna Lucia Krupp: Hello, my name is Anna Lucia Krupp. I am the founder and President of the Midwest Endometriosis Association. We are a nonprofit and we are based out of the Twin Cities in Minnesota, although we are connected with some of the other midwest states as well. And I am also personally an endometriosis patient, so in 2017 after finally being diagnosed 10 years after I should have been, I started a nonprofit so that women can hopefully get diagnosed sooner. Our main goal is to educate the community, do community events to improve the lives of those with endometriosis in the midwest. And I am also a research and a scientific writer.

Priya: Thank you Anna. Valerie, please introduce yourself.

Valerie Landis: Hi everyone. Thanks for having me on the show. I work in fertility advocacy and patient education. I have an educational website mostly about egg freezing but how egg freezing can be used especially for endometriosis or PCOS called eggsperience.com . And then a fertility focused podcast called Eggology Club. I am a multi-freezer myself so that is part of the resources I hope to bring to the discussion today.

Priya: Thank you Valerie. Dr Senapati, it is such a great pleasure to have you here with us again. For the audience, the expert we are featuring today is Asst Professor, Obstetrics and Gynaecology from the Hospital of the University of Pennsylvania. Dr Senapati what we just heard is our patient panel going to discuss the topic with you. But before we actually dive into how to manage endometriosis that may lead to infertility, I think it is important to define what endometriosis is first. So Dr Senapati, what is endometriosis and what are some of the symptoms that it presents with?

Dr Suneeta Senapati: Absolutely. Well, first of all Priya, thank you for having me on the show. And I'd like to thank all of the panelists as well. Seems like they are all going to bring very unique perspectives to this conversation that I think will be very helpful. So to start off with, endometriosis is a condition that affects about 10% of individuals who are born as females. And some of the most common symptoms that women can have can include painful periods, pelvic pain or abdominal pain that exists both during periods and outside of periods. And another common complaint can be pain during sexual intercourse. Some women with endometriosis may also have some irregularities in their menstrual cycles particularly some spotting just before their period is due. And at this point, endometriosis is a condition that can be suspected based on symptoms.

But at this point it really does require surgery to make a definitive diagnosis. And so, endometriosis is a condition which the cells that are typically in the lining of the uterus or the womb actually present in other places, so we can see them as lesions or spots inside the abdomen. Sometimes we can see cysts on the ovaries called Endometriomas, or it can present as more of a fibrotic disease type that causes internal organs to stick together. We don't know exactly what causes endometriosis in terms of why some women develop it while others do not. But there are some clear risk factors. And, we do know that it is an estrogen dependent disease that can really present very differently from one person to the next. I think one of the most important things to know about endometriosis is to understand what the symptoms are. And as many of the panelists alluded to, a lot of women suffer in silence for a long time and sort of the average time to diagnosis of endometriosis can be many years after the initial symptoms presents. So, it's something that we certainly want people to be more aware of in terms of how it can present, so that we can really direct people to who, who needs treatment.

Priya: You did mention that pelvic pain as a symptom for endometriosis. But I believe pelvic pain also occurs due to other medical conditions. So how do you differentiate between pelvic pain due to endometriosis or for something that is due to some other medical conditions, for example, interstitial cystitis or fibromyalgia?

Dr Suneeta Senapati: It's a great question. And we do see is that many women with endometriosis can have multiple different types of conditions that can cause pain syndrome. So for example, some women with endometriosis may also have fibromyalgia or interstitial cystitis. I think in terms of really differentiating where is the pain coming from? And therefore what's the best way to help treat the pain, really gets that understanding some of the other symptoms that may be present. So for example, if patients have pelvic pain that seems to be more related to when they have a bowel movement, for example, there are more problems with diarrhea and constipation that may point more towards an irritable bowel-like syndrome. And certainly similarly, if it's a bladder condition, they may notice more discomfort when urinating. So kind of understanding what are the other symptoms that come with the pain, can be very helpful.

And also many patients with endometriosis may notice that the pain is more cyclic meaning they'll notice it more kind of leading up to, or kind of during the times when they're actually on their period. So the cyclic nature of the pain in some cases can help point more towards endometriosis than some of the other conditions. But I do think it's important to kind of, anytime we see this, we really try to do a comprehensive assessment of other things that could be going on so that we address the endometriosis, but certainly can make sure that we are identifying and therefore providing the opportunity to address other syndromes that could be happening at the same time as well.

Priya: Dr Senapati, this is just my curiosity. When I was reading up, preparing for the talk actually, as you said, I saw many of the symptoms mentioned what you have just mentioned. So, in your years of treating endometriosis have you ever seen something which is so very uncommon, so very uncommon presentation of this condition and too difficult, initially to diagnose as endometriosis.

Dr Suneeta Senapati: Yeah, so, every once in a while we'll have some pretty unusual cases of endometriosis. For example, patients that actually ended up in the hospital because she was coughing up blood every time she got her menstrual cycle, suggesting that she actually had endometriosis involving her lungs and kind of was developing fluid collections related to that. So that's, one example of some of the more unusual cases that we see and I think really speaks of the fact that while there's some things that are very typical of endometriosis, it can also in some rare cases actually cause problems outside of kind of the typical gynecologic types of conditions and problems that people see women's health care providers for. And so I think those are situations where it can be really helpful to kind of approach things from a multidisciplinary perspective and really kind of keep it at the back of one's mind anytime you're evaluating are kind of treating a woman who is of reproductive age, is this something that could be related to her cycles and possibly endometriosis.

Priya: Dr Senapati, you did touch upon the causes of endometriosis but we really do not know the causes of endometriosis. So my question is endometriosis has been associated with several chronic diseases like you just mentioned, and then you have cancer, autoimmune disease, asthma, allergic manifestations and cardiovascular disease. Can you talk a little bit more about the of endometriosis? Also I want to club one question that came in. I think this was one of the first questions that came in for this talk. Some women with endometriosis may also have other immune disorders like eczema, asthma and fibromyalgia. Are you saying that endometriosis is an immune disorder?

Dr Suneeta Senapati: So it's an interesting question and I think it gets at the idea that while we've made a lot of progress and learning ways to treat some of the symptoms of endometriosis, we don't fully understand yet what exactly causes endometriosis or kind of more specifically why some women get it and others do not. Some of the theories are kind of ideas behind what may be causing endometriosis. One of the more popular theories has to do with the idea of retrograde menstruation or that some of the blood and endometrial tissue can kind of get flushed back into the abdomen when a woman is menstruating and in a subset of those women, they can form these lesions or spots. There's also some theories about coelomic metaplasia or basically cells changing a little bit inside the abdomen.

The idea that endometriosis can spread through the blood and lymphatic system which can explain some of the more distant sites of endometriosis that we see. And there are still others that believe that there may be kind of a genetic or multifactorial components to things. What we do know is that endometriosis does seem to be an estrogen responsive disease, meaning if we block estrogen or some of the hormones, or I should say enzymes that make estrogen, that can sometimes help with the treatment of the symptoms. And we've also seen that there can be a component of the immune system that may be altered. So immunomodulatory effects may be slightly altered in women who have endometriosis resulting in a state of kind of chronic inflammation, which is why I think it has been associated with many other types of chronic diseases in which inflammation or altered immunomodulation may be part of the spectrum. So, in response to the question, is endometriosis an immunologic disorder? I think it's in part, I think that it's a hormonal disorder, it is an immunologic disorder and I think it can manifest in a lot of ways that can be linked to other disease processes as well.

Priya: Thank you doctor. So we come to the topic that we're discussing today. So how does endometriosis lead to infertility?

Dr Suneeta Senapati: Yeah, so, endometriosis is an interesting disease in that it can be linked to infertility. And about 30 to 40% of women with endometriosis may struggle with infertility, which is actually much higher than what we see in kind of the general population. The ways that we think that endometriosis can cause infertility include changing the eggs, basically can be linked to changes in the egg quantity or quality. We see the endometriosis can be linked to diminished ovarian reserve which is kind of an independent fertility diagnosis. We've also seen that endometriosis can certainly change the pelvic anatomy and we can see that in the fallopian tubes in terms of causing scarring or distortion of the fallopian tubes. We've also seen that in some cases that can alter how a pregnancy implants inside the uterus or specifically altered both hormonal functions from the perspective of progesterone resistance on the endometrium as well as some other cellular mediated functions.

And as I mentioned before, endometriosis is the state of, there tends to be a lot of inflammatory cells and we think that that may alter kind of the peritoneal environment or that the general environment in which a pregnancy is occurring. So all of those factors can independently contribute to why a woman may be having difficulties conceiving. And we tend to see those kind of manifest either individually or in kinds of multiple aspects being affected in many women.

Priya: I do have a couple of more questions for you, but being mindful of time, I'm going to hand it over to Casey to start with hers. Casey is an endometriosis and infertility advocate. Casey please ask your questions.

Casey Berna: Hi. So I was wondering endometriosis can be, and you talked about this a little bit before, a complex multisystem disease to treat. There is the research that showed that there's things to endometriomas and the base of bowel disease. So I guess my question is, and I know I had endometriosis, my bowels and my bladder, what multidisciplinary treatments do you recommend to patients to help with chronic inflammation and pain, sort of even outside of fertility treatment?

Dr Suneeta Senapati: Sure. So, I think in any patient with endometriosis or in whom you suspect endometriosis, I think some of the tenets of approach involve understanding what are the symptoms that are most debilitating to the patient – why is she here to see us? And then how can we address the symptoms directly. But also thinking about sort of from a more holistic perspective, preventative measures on down the road as well. So that may include working with the gynecologist on different types of hormonal management, either birth control pills or gonadotropin releasing agonist or aromatase inhibitors. There's many classes of medications for that. It may involve surgery. It may also involve recognizing that above and beyond sort of the symptoms directly, that it may also be impacting a lot of other aspects of their life. So for example, if women have chronic pelvic pain, it can change sort of how their muscles sit in the pelvis or they can have situations where they have pelvic floor dysfunction and they may benefit from things like pelvic floor physical therapy.

Many of these patients are in a situation where they are in and out of work and it's significantly impacting their quality of life. And there's absolutely an increased, we see an increased prevalence of depressive symptoms and anxiety symptoms and identifying that and making sure that patients have access to mental health support and other sort of lifestyle treatments that can help above and beyond sort of the medication and the surgery I think are also very important. You mentioned endometriosis in the bowel and the bladder. Oftentimes in severe cases, we do also collaborate with gastroenterologists and colorectal surgeons and urologists are really kind of specialists in the organ systems that are involved above and beyond simply the uterus and the ovaries. So I think that in every situation it's really important to get an understanding of what all is involved and then being in a setting where you can provide that are really have access to that multidisciplinary care is really important.

Casey: I agree. I think multidisciplinary care has helped me a lot. You talked about surgical specialists who operates on a team who is able to sort of excise the disease and then having the multidisciplinary supportive health floor therapy and mental health support, acupuncture, nutrition, that that definitely all has helped me kind of thrive and manage my inflammation and my pain. My next question is, if a young patient has been diagnosed with endometriosis or has a family history of endometriosis, what steps do you recommend that they can be proactive about their fertility?

Dr Suneeta Senapati: Yeah, so Casey, this is a great question and it's one that I think is certainly going to be evolving, particularly as fertility diagnostics and treatments continued to evolve. I think the first step is having the conversation and I think a lot of times the focus is on the symptoms that are in front of you. So, dealing with the pain, dealing with the irregularity and the cycles and pain with sex and all of those elements. But also I think it's important to open the discussion early in terms of if someone has a diagnosis of endometriosis, what does this mean in the future for them? As I mentioned not everyone with endometriosis is going to have difficulties getting pregnant. And typically what I advise my patients, let's say they've had surgery and they're now on birth control pills to suppress their periods, I usually tell them, when they're ready to start a family stop whatever contraceptive method is being used, whether it's an IUD or a birth control method, try for somewhere in the range of six months.

But certainly track the cycles in between there as well. Because I would say that most providers will say try for a year if someone is under the age of 35. But I think in patients with endometriosis, we need to have a slightly heightened awareness that some of these patients are going to have more trouble. And so I think having it on the radar to have the discussion and see a fertility specialist on the earlier side of that process is important. I think some of the other modalities in terms of fertility testing metrics, things like ultrasounds to look at antral follicle counts and anti mullerian hormone levels. We're still trying to understand how best to utilize that information and in terms of counseling people who needs to be I guess worried so to speak earlier versus not.

I do also see patients that come to see me interested in freezing eggs, for example, knowing that have endometriosis and just not being ready to try to build a family quite yet, but to potentially have that option available to them in the future. So, I think all of those are important to discuss. And again, every patient is going to be a little bit different in terms of what they're experiencing and what their prognosis may be moving forward. But I think the first step is like I said just to start the conversation so that it's on the patients' radar, their provider's radar so that it is something that even once a year can be, can be readdressed and potentially find the right time to intervene if appropriate.

Casey: Excellent. I know you talked a little bit about the classic endometriosis symptoms, and they can be painful periods, pelvic pain, ovulation pain, painful intercourse and also painful bowel movements, leg pain, back pain. It could sort of, there could be a lot of symptoms, chronic fatigue, but also some patients are asymptomatic and the only sort of sign of them having endometriosis may be that they are having trouble conceiving. Have you found this to be true in your practice as some of your unexplained infertility patients were actually, have you found them to actually be endometriosis patients upon diagnostic lab?

Dr Suneeta Senapati: Yeah, it's a great question. And I think that the answer is yes. So we absolutely see people who initially come and their primary reason for seeing us is because they're having difficulties getting pregnant. And then as we go down the route of additional diagnostic testing, it may be that on an ultrasound it looks like they have an endometrioma or if in kind of conversations we then realize that oh, I guess I do have painful periods. But I guess I never really thought that they were any worse than anybody else's. I can't tell you how many patients say exactly that to me. They say, well, I just thought that this was part of being a woman. And then when we go in and do the laparoscopy, we'll see endometriosis.

I think one of the really interesting and tricky parts about endometriosis is that we see time and time again, that the symptoms don't necessarily correlate with the disease that is seen. Whether that is at the time of surgery or difficulties with infertility, we just really see very little kind of correlation between how much we see at the time of laparoscopy and what a woman experiences. So I think, my approach to it is to really be have it on my radar as a potential possibility. And if after further kind of further investigation, I strongly suspect it, then that is a situation in which doing a laparoscopy or the next steps may be helpful. Now there are also patients with endometriosis who if they are otherwise asymptomatic, we may just simply suspect it based on ultrasound findings that we may go straight into fertility treatments as well. And both of those are acceptable. But again, I think it really comes back to having the discussion with your doctor in terms of what are the symptoms, what are we seeing and what is the best way to treat this both in the short term and the long term based on symptoms and current goals.

Priya: Thank you very much, Casey. We will round back to you if you have more questions. Next we have with us Heather Arnold Brown who was diagnosed with endometriosis in 2016. Heather please ask your questions.

Heather Arnold Brown: Okay. Endometriosis and retrograde menstruation coincide together from your experience, would you say either or both affects the quality and mobility of the eggs?

Dr Suneeta Senapati: Yeah, so I would say that, potentially both can impact the quality and mobility of eggs as follows. So, you know, retrograde menstruation is one of the theories that has been described to explain why endometriosis may happen. What's interesting is that most women actually have retrograde menstruation, but only some of those women have endometriosis. So it doesn't fully explain why endometriosis happens. But in theory, in some women, that could be sort of the first step in getting some of that endometrial tissue into places where it's not supposed to be. In terms of the quality and the mobility of the eggs, there are some studies that have suggested that the egg quality may be compromised by endometriosis. There aren't good ways to test that in patients right now. A lot of people will use surrogates like some of the other ovarian reserve test to try to try to understand this better. as far as mobility, the eggs that can really refer to, to a couple of things.

One, someone's ability to release an egg and most of the time the ovulation part isn't dramatically impacted by endometriosis. But the other piece of mobility can come into play when people are going through fertility treatments, like in vitro fertilization for example, in which a surgery is needed to extract eggs. And sometimes if endometriosis has changed the anatomy that can make it a little bit more difficult. So in summary, I would say that we can see both endometriosis in retrograde menstruation together. And it's probably the endometriosis inherently that affects egg quality and mobility more so than retrograde menstruation alone.

Heather: Okay. That makes sense. My second question, in many cases, endometriosis patients experience this pain which is painful intercourse. What are some tips you suggest where sex or intimacy won't feel as uncomfortable or like a task or a chore?

Dr Suneeta Senapati: Sure. So yeah, painful intercourse is something that a lot of patients will describe or kind of elicit on unquestioning. A couple of things that can be helpful. One, certainly making sure that lubrication is involved and there are some types that are better for women who are actively trying to conceive versus not. Some women that have pain during intercourse may also have pelvic floor dysfunction. And so this is a situation in which things like pelvic floor physical therapy can help relax some of the pelvic floor muscles and make it such that intercourse is less uncomfortable. Depending upon what other treatments are involved, there are some women who, particularly if the endometriosis is happening sort of behind the uterus and what we call the rectovaginal space. They may benefit from certain surgical techniques to destroy the endometriosis in that area. But I think it's certainly kind of approaching things from all of those perspectives is important. It may be that one works better than the other or it may be that for given woman all, all three of those may be helpful.

Heather: And my last question, the curriculums for endometriosis averages about 20 minutes or so. So what are some steps that we can take to get more doctors educated and aware of the severity of Endo, making it easier for an earlier diagnosis as well as proper treatment?

Dr Suneeta Senapati: Yeah, so I think one of the most important things that we can do is to raise awareness about endometriosis certainly amongst patients so that they're asking about it, but also on the medical community side, we do a lot of education with our residents and fellows about endometriosis, both kind of sit down conversations like this, but also encouraging people to think about it anytime someone comes into the office or into the emergency department with abdominal or pelvic pain. I really think that it should be sort of on the list of things that people are thinking about from the get go, along with other kind of other disease processes too. So, I think that that making sure that it's a staple part of medical school curriculum is helpful.

But also I think all women's health care providers many patients will see nurse practitioners and physician assistants and they do a great job taking care of patients. And I think the more that the world and the more that our general community is aware that this is a real problem. I think that's really going to help patients get access to the care that they need and sooner. I think the sooner we can get people in and really taking taking care of appropriately, the better it will be for everyone.

Priya: Thank you Heather. Next we have Valerie Landis with us. She focuses on guiding women of reproductive age through complex and challenging parts of fertility decisions. Valerie, please ask your questions.

Valerie Landis: Hi Doctor. Thanks so much. So what are some of the new proven tests and/or scientific medical advancements in the marketplace that we can help not only diagnose endometriosis better but manage some of the symptoms. Are there any new research or tests out there that you would recommend? Like have you heard of receptivadx. Would that be a good option for patients?

Dr Suneeta Senapati: Yeah, so I think this is definitely an area that's still evolving for certain and I think there's lots of groups that are working on both diagnosing endometriosis early and really targeting new therapies for the treatment of endometriosis. There are some tests that have been developed that specifically look at the endometrial receptivity and the idea and that's the one that you had mentioned, and it's the idea behind it is that they're in women with endometriosis, there are certain markers that are present in the lining of the uterus that may be expressed differently. The one that you mentioned in particular looks at something called a BCL6. So, I think that that particular test was developed to really look at patients who are struggling with fertility issues. And I think that as with any new test, we need to make sure that we are assessing how does it perform in patients that we know have endometriosis versus those that don't. And, I really look forward to these next couple of years because I think that there are a lot of interesting new options that are going to come down the pipeline that may help us to both diagnose endometriosis sooner. And particularly for patients with fertility, help them to navigate the IVF process a little bit better. So I think at this point, those tests are still pretty new. So, I don't know that they've been sort of universally utilized yet, but certainly they have a lot of promise.

Valerie: Great. And does birth control mask endometriosis in any way or help the symptoms and like when do you recommend fertility treatments or egg freezing for patients that are suffering from endometriosis?

Dr Suneeta Senapati: So, those are great questions. I'll start with the birth control ones. So in answer to your question, does birth control mask endometriosis? So birth control and all the various methods, whether it be pills or an intrauterine device or the implants, they are very common methods used to treat the symptoms of endometriosis. And so utilizing those message should be, should be encouraged. I wouldn't tell someone to not utilize those methods for fear of being underdiagnosed or misdiagnosed. They're very effective both for contraception but also for managing some of the symptoms that can come with endometriosis, like painful periods or even pain outside of periods. I think that what's important is that if someone has been on birth control for a long time and then are stopping the birth control pill to either to take a break or even for the purposes of trying to start a family, I think it's really important to kind of take stock at that point of what symptoms may be present.

So there are many women who feel great when you're on the birth control pill and then the moment that they stop it to start to have a family, they're in horrible pain. And so that's a situation in which I would really see a gynecologist or potentially a fertility specialist sooner rather than later, because those are patients in whom they may need additional management in that process of trying to get pregnant that can either expedite the process or to help manage some of the symptoms as they go through them. And I believe your second question was about egg freezing and it’s kind of when should one potentially consider fertility treatments like egg freezing. And this is an area that is, there aren’t clear guidelines at this point. What I usually tell women is that if you have endometriosis and you’re in your late twenties, early thirties and are starting to think about having a family but are not necessarily in a position to or are worried because you’ve had prior treatments that you’ve been told you have bad endometriosis, I think that’s the timeframe that is most appropriate to begin the discussion.

Dr Suneeta Senapati: Egg freezing may not be right for everyone, but I think it’s really important that every woman has given the opportunity to talk about it, particularly if they have a gynecologic condition that could impact their fertility. And so that’s generally the timeframe in which I advise patients to start those conversations. And if they are going to potentially go through egg freezing, we usually say the earlier age, the better. But that is a more involved conversation. There may be other kind of medical factors that are involved. And also certainly every woman is different in terms of what her reproductive narrative looks like. So that’s also an important part of that conversation.

Valerie: And endometriosis has been linked to infertility reasons between 30 and 50% if that’s correct.

Dr Suneeta Senapati: Yep, that’s correct.

Valerie: So the egg freezing or fertility treatments then help with endometriosis?

Dr Suneeta Senapati: So that’s a great question. Yeah. So, from what we can tell going through the process of fertility treatments to either bank eggs or embryos or to conceive, does not appear to really significantly alter the course of endometriosis. Some women will report that when they are pregnant, a lot of the symptoms that they experience during when they were not pregnant are not as profound or may go away entirely. So that suggests to us that the process of getting pregnant or being pregnant does not seem to hurt the endometriosis or make it worse. If anything, you may see some symptomatic relief during that time. Egg freezing, the research so far has not suggested that it causes a progression in endometriosis or worsening symptoms. There are some hormone treatments that are involved in many fertility treatments, but they are usually short term, um, usually for a few weeks at a time. So from what we can tell, they do not substantially alter endometriosis or the risk of symptoms.

Priya: Thank you Valerie, thank you Dr. Our next panelist is Anna Lucia Krupp. Anna is founder and president of the Midwest Endometriosis Association. Anna please ask your questions.

Anna Lucia Krupp: Hi Dr Senapati. How are you? So I know you’ve talked a little bit about delays in diagnosis. So you’re in the United States. I think that the average is between five and 10 years. I know it took me personally about 10 years. So in your opinion, what factors are impacting the delay in diagnosis? I know you’ve discussed it a little bit, but if you can just speak a little bit more about what patients, doctors and advocates can do to make sure that we receive early diagnosis and treatment.

Dr Suneeta Senapati: Sure. I think that one step is certainly on as a healthcare provider, it’s asking the question. So asking the question about symptoms or asking the question about and not simply asking the yes or no elements of the question, but to dive a little bit deeper. So one of the things that I alluded to was just the concept of painful periods and that it’s very common for women to experience some discomfort during periods. And I think many women with endometriosis kind of deal with that thinking that it is within the spectrum of normal. But then when I asked more questions about, well, how bad is the pain and what are you taking to manage the pain? And when you take medicines like Ibuprofen, does it help the pain? If someone tells me that they’re taking medicine pretty much around the clock when they have their period and it’s not really changing their pain at all, then that is a little bit of a flag to me that maybe there’s something else going on that warrants additional evaluation.

And so I think that one of the best things that we can do, and this is a just kind of from a public awareness perspective and also as a healthcare provider, one of the best things that I can do is ask the question. But also I think from a patient advocacy perspective, a lot of this is also about educate young women about these are, it’s almost a part of health education in some ways. These are the normal changes that all women experience and that these are some things that,so these are some symptoms that can happen and talk to your doctor if you feel like you’re experiencing something that you’re not sure about. I think just allowing that is important. I think a lot of girls may not feel very comfortable talking about their periods. And so I think just having that awareness that it is okay to talk about something like thi, whether it’s with someone that you trust or with a healthcare provider, that that is often the first step that allows us to then say, okay, it looks like we need to do more investigation.

Anna: Yeah, absolutely. And I think that kind of leads into kind of the idea of normal periods and the stigma around menstrual disorders and pelvic pain and how that kind of impacts the diagnostic process for women with endometriosis. I don’t know if you’re familiar, there’s a whole body of literature, even just on the experience of women with endometriosis and being told that their pain is normal by family members, especially even just like these, because it does run in families. There’s mothers with endometriosis and experienced painful periods that never were diagnosed. And then, they tell their daughters that their pain is normal without knowing. And then they go to the clinicians and the same thing kind of is cyclic and told nd so those patients never get diagnosed until 10, 20 years later. One question I did have for you, so you spoke about using ultrasound and how surgery really is required to confirm a diagnosis and in practice, I think a lot of the time ultrasounds and even MRIs are used to rule out endometriosis without surgery. And so can you speak to that and how that can be harmful to patients? Because I know there’s a lot of patients out there that have been told that for example, we didn’t see anything on your ultrasound. And since endometriosis can be on a pelvic organs that are not visible by an ultrasound of the ovaries, there’s a lot of misinformation and confusion kind of in the patient community there and if you can speak about that, that would be helpful.

Dr Suneeta Senapati: Sure, absolutely. So, I think the imaging modalities like ultrasound and MRI can be helpful in some settings. So, for example, if someone has a cyst that is on their ovary, it can be helpful in differentiating, does this look like the kind of suspects related to endometriosis or not? But from purely a perspective of does somebody have endometriosis or not? Well, there’s some subtle findings that can be picked up on ultrasounds and MRI. Really at this stage, there’s a reason why as of right now, the gold standard is still surgery and that’s because of exactly what you said in that, subtle things like the lesions themselves, unless they’re a form of deep infiltrating endometriosis, they may not be visible on imaging. And so I think oftentimes when women present with pain, the first, it’s very common to have imaging initially to rule out serious things that might need emergent intervention, like a ruptured cyst or ovarian torsion.

But I think the follow up to that is, someone is still having pain and we’re really not seeing any signs on imaging of an explanation. I believe that there is a role there for a diagnostic laparoscopy, which is a minimally invasive procedure that can be done in the outpatient setting to take a look. And not everybody with pain is going to have endometriosis, but I think before telling someone that they definitely don’t have endometriosis, if someone has cyclic pelvic pain, I think that there’s definitely a role for that diagnostic laparoscopy there.

Anna: Definitely agreed. I know we’re running out of time, but I’ll just ask you one more question. So I know one experience I had as a patient is that I was also diagnosed with something called Endosalpingiosis, which is kind of a variance of endometriosis. Can you speak to endo and endocervicitis and how those diagnoses can confuse patients? I know in my case, I actually have both. So that’s a unique, but some patients only have Endosalpingiosis and are told that they don’t have endometriosis and that others are given the same treatments and told that they should treat it the same. So if you could speak about that, that’d be great.

Dr Suneeta Senapati: Sure. So, endometriosis can have a spectrum in terms of how it presents in the pelvis and outside. And so, there are some conditions like Endosalpingiosis or even adenomyosis that’s another condition that is linked to endometriosis. And I think that it’s important to recognize sort of similarities and differences in terms of what the diagnosis means versus what the treatment means. And so many of the same treatment modalities are used for all of those disorders. Because if the predominant symptom is pain, then the idea is that treating either the hormonal elements or again, things like the enzymatic elements with aromatase inhibitors may be helpful. However, how that may manifest from a fertility perspective may be very different as well. So I think that I think it's important to understand that there is a spectrum of organs that can be affected by endometriosis and that each situation is going to be different based on what the symptoms are, what is seen either on imaging or at the time of surgery and what the treatment goals are.

So, the treatment goals may be very different for a young woman who hasn't completed her family compared to a woman who has. And so this is a scenario in which I would say, talk to your doctor to understand how does this impact not just what I'm experiencing now, but what could happen in the future so that whatever treatment is decided upon can potentially address both things that are happening now as well as the future.

Priya: Thank you Anna and Dr. That was an awesome set of questions from everybody on the panel. We now throw open the discussion. So I mean, you can take some audience questions. Dr Senapati, the first question that has come in is, the person writes about her endometriosis. She says, I live everyday feeling like a robot forcing myself through the motions because endometriosis, adenomyosis, and fibroids have destroyed anything inside of me that was human. And then she explains about her treatments. I'm just going to cut the short. But her question is what is the medical research community doing for women like me and can I expect something more than just being told to take 1200 mg of Ibuprofen down three times a day and deal with it. So in other words, maybe you could talk a little bit about latest research that's happening in the field.

Dr Suneeta Senapati: Sure. Yeah, that sounds like a tough situation. One thing that I can tell you is there's definitely a lot of interest in the medical community and in making things better for patients with endometriosis and recognizing that while we've come a long way, we still have a long way to go. So some of the treatments that have been explored are other types of medications that either act at the level of the brain. So things like gonadotropin releasing antagonists or that act kind of directly at the level of the individual kind of endometriotic lesions or implants. So things like progesterone receptor modulators are being studied. And there was actually, there's some interesting things that are coming out of the basic science research as well and some mouse models that have looked at, different components that are produced in more commonly in patients with endometriosis that, like Galectin-3 that can be linked to inflammation and the formation of new blood vessels and fibrosis and all of the things that cause some of the symptoms that patients experience. It takes some time to get things from sort of the bench to the bench to the bedside.

But people are definitely very interested in this and continuing to work on this. And there's clinical trials all over the US for some of these newer agents. So what I will say is I hear your frustrations and we are working on it to the best of our ability.

Priya: Thank your Dr. We will take another question. What are some of the precautions that women with endometriosis need to take while trying to conceive?

Dr Suneeta Senapati: Okay. So that's a great question. I think that one of the things to be aware of is that, for one, there's some women who do okay when they're off of medical management as they're trying to conceive. Others will notice that their symptoms get progressively worse. So I think, working with your healthcare provider and sort of setting a setting timelines and goals and points of reassessment are very important. So as I had mentioned previously, I usually tell people try about six months and if you're not pregnant in that timeframe then that's a good timeframe to at least start the conversation with the fertility specialist. I think it's also important to know that many women with endometriosis, their fallopian tubes can be affected, which may put them at an increased risk of ectopic pregnancy or a pregnancy that could implant outside the uterus. So in women that have endometriosis, I always advise them that if you do get pregnant, it's important that you see a healthcare provider as soon as you know, so that they can reassure you that the pregnancy has implanted in the right place and that things are looking appropriate moving forward. So I think those are the two most important pieces of advice that I can give.

Priya: Thank you. Doctor, we have another question. It says, if you have decided to do egg freezing as 34/35 and are a few years off trying to conceive, but symptoms are highly suspicious of endometriosis, is it better to postpone a laparoscopy until ready to conceive or best to investigate now to confirm a diagnosis and excise any endometriosis if found? What are the risks of waiting?

Dr Suneeta Senapati: Sure. I think the decision to consider surgery is one, that it warrants a conversation between the patient and the surgeon and some of the factors that go into deciding when to do surgery, have to do with the patient's medical condition overall. So other medical problems, prior surgical history, other things that might be going on in someone's medical life. But I think also most importantly the symptoms. So, I usually guide patients on whether or not to consider surgery based on the severity of symptoms. And if this is a situation where, someone says I feel like my periods are getting worse or I feel like I'm having more pain over time. I think it's better to look sooner, both for diagnostic purposes as well as for therapeutic purposes. Even if one does not anticipate getting pregnant in the short term, I think from the perspective of a kind of knowing, what we're dealing with, what's the cause of pain cause endometriosis is one cause, there may be others, but also potentially addressing it moving forward.

So for example, if a patient comes to me and says that I'm not quite ready to have a family yet, but I've noticed more discomfort, we do a laparoscopy, diagnose and treat endometriosis, that may be a scenario in which I advise to consider hormonal management like a birth control pill or an IUD until she is ready to have a family, as opposed to not being on any medication and then there's a greater chance that her symptoms may recur in that setting. So I think it's a dynamic discussion but it's often driven most by the symptoms that the patient is experiencing.

Priya: We have two more minutes, so maybe we can just take two more questions. The next one is how a stage of endometriosis related to infertility. I think she wants to know do women with stage or very severe endo always suffer from infertility and vice versa or do women with mild endo have lower rates of infertility?

Dr Suneeta Senapati: So, it's a great question. Endometriosis is one of those tricky diseases that both from a pain perspective as well as an infertility perspective, the stage of disease, which is something that is classified at the time of surgery, does not necessarily correlate with fertility or with or with symptoms in general. Now at the time of surgery, if for example, there is a concern that both fallopian tubes have been impacted, then that's a scenario in which that particular presentation may be much more likely to lead to infertility. And I think that it's important for women to be aware that even stage one endometriosis can cause infertility but having had a history of stage four infertility or a stage four endometriosis does not automatically mean that you cannot get pregnant.

So I think the flip side of this conversation is don't assume if you have endometriosis that it's impossible for you to get pregnant, It's not a good time in your life to be building a family, make sure that you're using contraception, etc. But the opposite side of that is if you are someone who has endometriosis and it has taken six months to a year to get pregnant irrespective of what stage of disease you were told that you may have, that is a scenario in which you should see a fertility specialist.

Priya: Thank you doctor. I think we have to wrap up now. Endometriosis is a debilitating condition in which a tissue similar to uterine tissue is found outside of the uterus, most often in the pelvic cavity and on surrounding organs causing chronic pelvic pain, infertility and many other symptoms. Thank you Dr Senapati for sharing all the great information. I think you are truly wonderful and I'm sure you've shared so much information that would help the audience manage the condition better. Valerie, Casey, Anna and Heather, thanks so much for participating and bringing fore the patient perspective to this discussion. I know actually the questions continue to come in, but we have to wrap up now. Probably we will have to arrange a Part 2 for this Dr Senapati because I am still seeing questions coming in. Thank you once again. And we also thank the University of Pennsylvania and the audience. The talk will be available on curetalks.com and CureTalks@Penn, so please visit our website for details on upcoming talks. Thank you everyone and have a great evening.