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Donna Mazyck:

Welcome to the School Nurse Chat podcast. Today we'll be talking about endometriosis. We're going to learn about it, and we're going to be aware of what our role is in this issue that affects many. Our guests today are Tara Hilton and Dawnyel Furlong.

Welcome, Tara. Welcome, Dawnyel.

Tara Mangum:

Hey, thank you so much. I'm so happy to be here.

Dawnyel Furlong:

Thank you. Happy to be here as well.

Donna Mazyck:

Tara, would you share with our audience how you got into this world of being a founder and executive director of a nonprofit dealing with endometriosis?

Tara Mangum:

I was born and raised in Wichita, Kansas, and I spent a lot of my high school years in pain and just feeling isolated and different than everyone. It was normalized.

Later on in life, when I finally was diagnosed in 2006, I just decided that I wanted to use my patient journey and everything that happened in between the onset of my symptoms till official diagnosis to help others. And honestly, my mission was just to make sure no one battled alone. The most common feeling I had was just always being alone and not having information or any support.

That's when I decided to officially found a nonprofit and we titled it Yellow Cape. I feel like I wasn't going to let it be a negative, so I put on my yellow cape and I'm there to help others with everything that I had learned.

We started that off in 2017, and then since then we've just provided support and advocacy and just education to thousands and thousands of individuals battling endometriosis.

Donna Mazyck:

Dawnyel, please let us know a bit about you.

Dawnyel Furlong:

My name is Dawnyel Furlong and I am from Delaware, the East Coast. My nursing background is from the operating room, working in post-anesthesia care unit and in nursing education before I became a family nurse practitioner.

But in addition, I also work as a school nurse in a small charter school in Delaware. And I am a mom of two young children who enjoy keeping me busy and they love going outside and we visit the beach frequently.

Donna Mazyck:

To begin our discussion for you, Tara, tell us about menstruating students. What is primary dysmenorrhea?

Tara Mangum:

One of the things we try to share in our community is that the primary dysmenorrhea is what a lot of adolescents experience, right, so I think something like 90% of everyone that menstruates have the primary.

Well, it's basically painful menstruation in the absence of any pelvic pathology. So if you're having chronic pelvic pain, but you haven't had any pathology to suggest secondary, that's generally how it's defined in the medical community. I don't know if you want me to go into like the personal symptoms, but that's how we define it here at the Yellow Cape.

Donna Mazyck:

Thank you, Tara.

Dawnyel, in your work as a family nurse practitioner, can you give us insight now that we've heard what primary dysmenorrhea is, what is secondary dysmenorrhea?

Dawnyel Furlong:

Secondary dysmenorrhea is painful period, but unlike not having a pelvic pathology, secondary does include some pelvic pathology, most common, endometriosis.

Donna Mazyck:

Okay, thank you for that. So we know what we're dealing with, we know that adolescents can have painful periods, but in what ways are those painful periods with no pathology, that primary dysmenorrhea, how is that addressed?

Dawnyel Furlong:

Primary dysmenorrhea in the school setting with a parent approval, your first-line treatment should begin with NSAIDs. This helps block the prostaglandin production, and most of your adolescents and teens will report relief with their NSAIDs.

A small percentage might not respond to the NSAIDs, and, as a school nurse, that's when we can have the discussion about following up with like their pediatrician and their GYN because there may be a discussion there about the option for hormonal medication.

Donna Mazyck:

Tara, what are some of the signs and symptoms that students may experience with primary dysmenorrhea?

Tara Mangum:

The most common probably are pelvic cramps. You get some cramping, some bloating. Others may or may not have heavy bleeding, but the cramping, the fatigue, you may experience some hip and lower back pain, but those are usually the most common with the primary.

Donna Mazyck:

Okay, I appreciate that.

You mentioned, Dawnyel, some of the treatment. What other forms of treatment, other than medication, may exist when adolescents are experiencing painful periods?

Dawnyel Furlong:

Sometimes it's just getting back to basics. Did we have breakfast? Are we hydrated? Do we need to just rest for a couple minutes?

Sometimes just a warm compress laying down for a couple minutes for 10 to 15 minutes, if their school schedule allows, maybe having that ibuprofen or the acetaminophen, having a nice warm compress laying down in the nurse's office, if there's space available, because the nurse's office are usually very busy, but just kind of having a little bit of comfort and giving that time for the NSAID to start working and then seeing if we can go back to class.

Sometimes it's just not all pharmacological treatments, just sticking to some basics as well.

Donna Mazyck:

Okay, that's helpful.

Now we've talked about this, the painful periods, let's go into what endometriosis is. We touched on that with the secondary dysmenorrhea, but what is endometriosis and what's the prevalence in adolescent girls?

Tara Mangum:

The way that we define it, because there's so much debate in the community on theories of what it is and how it exists, we try to keep it very benign. So we define it as endometriosis as just being a condition where tissue similar to uterine lining is found outside of the uterine cavity. We don't focus on how it got there or any of the theories, but just basically the tissues found outside of the uterine cavity.

As far as the adolescents that it affects, we know that 90% experience primary dysmenorrhea. Of that 90%, the studies online show somewhere around 10 to 15% don't respond to the NSAIDs and over-the-counter pain medicines so of those are the ones that are thought to have the secondary.

The primary, I think as Dawnyel had said earlier, the primary cause there is usually endometriosis.

Dawnyel Furlong:

Now, I really enjoyed Tara's explanation because when you're working with adolescents and teenagers, anxiety is common and sometimes just keeping it very basic, like, "This is here. We are not going to worry about how it got there and worry about it. We're just going to treat what we have acutely right now."

The goal in the nurse's office is to ultimately get them back to class and then also to keep them in school because painful periods is like the number one reason for girls to miss school so sometimes just trying to keep them back into class, managing the symptoms.

Like Tara mentioned, there's not a actual number, but yes, most of the adolescents that had failed the treatment of the NSAIDs will be more likely to have endometriosis.

Donna Mazyck:

Just a follow-up question to that, when would a school nurse know, Dawnyel, to refer a student for further treatment?

Dawnyel Furlong:

We all build a relationship with our students and, especially if this is a monthly occurrence, we're probably going to have a great relationship with the girls. We're going to have a good medical history because we probably have seen them once a month or maybe multiple times in one month. So we can kind of gather a history and we can see is this becoming progressive? Are the NSAIDs not working? We gave the NSAIDs in the morning and they're still having pain. They've tried some other non-pharmacological treatments that's not helping with the NSAIDs, and you have that good history.

So maybe you have a conversation with the parents that this is what we've tried here in school. What have you tried at home and have you thought about reaching out to either the pediatrician or, if the adolescent does have a GYN, reaching out to them and just kind of give them the history and seek their expert opinion.

Tara Mangum:

I do agree with Dawnyel that the school nurses are a lot of times our frontline defense for the young girls.

When I think back to my own journey, I had a nurse that maybe wasn't knowledgeable, and so she had a stigma that everyone has bad periods so that wasn't helpful. Even though I was in there every single month, at least for a day or two laying in with a heating pad and crying and even trying to miss physical education because I couldn't bear to run a mile when I was feeling that way, nothing ever triggered anyone's radar that something might be wrong so I think the more awareness.

And because of that bias that might still be in there with some of the generations ahead of us, I always thought it would be great to have sort of a score-based checklist that would remove any bias. You ask these certain questions and if a certain score is reached, maybe the nurse would send something home saying, "Hey, there's a possibility that there's some symptoms of endometriosis. We suggest you maybe go to a GYN or reproductive endocrinologist and further check it out."

So yeah, I think being the frontline defense there and just really triggering that conversation, especially when they see repetitive behaviors, is definitely the best defense that we could have.

Donna Mazyck:

I really appreciate that perspective.

What would it look like, Dawnyel, from a school nurse perspective to begin some population-based awareness and education in addressing this chronic condition?

Dawnyel Furlong:

Yeah, I think before we were to go jump to just endometriosis, like also just giving a baseline, a base education about painful periods in primary and secondary. Sometimes primary can include some tough pain that we have to work through and just kind of give that support that as long as this is kind of our baseline, we can follow up with our pediatrician. But it's okay that you might have some radiating back pain or you might have other symptoms like diarrhea and nausea and vomiting, but then also knowing that if it's failing and then the giving the education that this could be secondary and this could be endometriosis and just talking a little bit about endometriosis and how it's very common in families like talking about if their mom maybe had endometriosis, how common that it could be for the student to have endometriosis and then have a nice baseline on when is the time to contact further attention from your pediatrician as the NSAID's not working or have you had pain from the very beginning of starting your menstrual cycle and it's just not improving, it's progressively worse.

So I think having some education in the school setting, but also keeping it enjoyable, too, because not all the girls want to talk about their period pain in front of other people. So how you can do it privately and comfortably, but also getting the message across that it's okay to have this, we just need to work through the symptoms.

Donna Mazyck:

Yeah, I hear you with that.

You mentioned the family, the generational experiences with periods, and sometimes in that family it can be thought that this is normal for us, but just being able to say when treatment doesn't help, when what you do to manage the symptoms just doesn't seem to help, that there is a way you can go. There is progression in getting the help that you need so I appreciate that perspective.

Tara, from a community-based setting and with the advocacy that you've done, what types of education and awareness have you done?

Tara Mangum:

Some of the things that we focus on obviously are awareness campaigns, but we also focus on the support side. The medical professionals are the ones working on everything that needs to be done to either get a cure or some other treatment options, but we just want to make sure no one's alone so we've focus on a couple of things.

We've created a brochure that's up-to-date with very basic vocabulary so they can understand without using large medical terms. Do you have this? Very simplistic. Do you feel like you have to urinate a lot? But just keeping simplistic symptoms.

We also provide support on talking to their parents about it. Like you said, if it comes from a family history, there may be some unknown bias and stigma like, "I had this, your grandmother had, this has been for five generations, you're no different." How can you break that cycle, but also have a valuable conversation that's productive?

But also more than anything, I think we've seen the mental health side of this and I think that's really where we focus our attention on because we've seen death by suicide rates just go through the roof in this community because they oftentimes feel like there's not a lot of help and they can't fathom thinking about 25, 50 more years of this. So really making sure we have support groups and that we buddy people up in our group and we're constantly checking in. We don't cure to claim, treat or provide any medical guidance, but we say, "Hey, of the people that have had this symptom, here are some questions you should ask your medical provider." So we just try to steer them in the right direction.

Lastly, I think a period tracking app is always very valuable and there's a lot of great ones out there, but it really helps you to go in prepared to your medical provider. So track that, track your symptoms on which days because it might provide some clarity.

Then lastly, people cringe on this, but social media. It is what it is. It's a great tool out there now and it helps people connect so they can go out there and do a lot of their own research and even see endometriosis specialists talk about it.

That's sort of how we wrap our arms around it from the support group side of it.

Donna Mazyck:

I want to thank you, Tara and Dawnyel, for just helping us to walk through what painful periods are and when it is time to really seek more treatment because endometriosis may be the issue. You've enlightened us today, and I think that you've given information that we can move further with. So thank you so much for being our guest today on School Nurse Chat.

Tara Mangum:

You're welcome. Thank you for having me.

Dawnyel Furlong:

Thank you.

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The Uterine Health Guide website is an unbranded patient-centered information resource that was created in response to needs identified by the Women's Health Patient Advocacy Community.

The Uterine Health Guide, UHG, was designed for patients living with uterine health issues to navigate their conditions and learn about menstrual health and period irregularities.

The UHG is intended to activate readers to take charge of their health, seek support, and talk to their healthcare providers.

This resource is the culmination of efforts by Myovant and Pfizer, guided by the Women's Health Patient Advocacy Community.