HYPOSPADIAS CONVERSATIONS

TRANSCRIPT: PSYCHOLOGISTS ROUNDTABLE DISCUSSION PART 2

Guests: Lillian Hayes, Ph.D., Jennifer Hansen-Moore, Ph.D., Jackie Papadakis, Ph.D. and Jeff Garofano, Ph.D.

JOHN: ***This episode of Hypospadias Conversations is brought to you by our sponsor, MyHypeLife.org.***

Wondering why you've never seen a TikTok, Reel, or Insta story about hypospadias? It's because they don't exist. Why? Well, it's because no one wants to talk about their privates online, let alone post a video blog about it. So we found a workaround. At MyHypeLife.org, you tell us your story in private. We turn it into a powerful TikTok video recreated by professional actors. Your face and name stay out of it, but your story gets told in a relatable, real way. Parents, girlfriends, guys with hypospadias, your story will help someone else feel seen for the first time.
We need your help to tell it. Visit myhypelife.org to sign up and participate. That's my hype (that's h y p e) life dot org. Let's put some TikTok stories out there for how to live a hype life with hypospadias.

JOHN: *Welcome to Hypospadias Conversations with co -hosts John Filippelli and Bonnie Steinberg. We are members of the community that have experienced living with Hypospadias and we want to begin the dialogue with members of that community, the men, women, and parents whose lives or the lives of those they love have also been affected by this common yet largely unknown condition and to create more safety to have these conversations.*

BONNIE: Dr. Garofano, how does one prepare the boy, the elementary school child, junior high, high school, for teasing, bullying, locker room situations that get testy?

JEFF GAROFANO, Ph.D.: Yeah, that's a great question, Bonnie.

BONNIE: We only ask the great questions.

JEFF GAROFANO, Ph.D.: Yeah, you're only asking great ones, that's right.

So, to echo my colleagues, I think preparation is a big part of this. I think skill building is a big part of this as well. So, from an early age, talking again as my colleagues did about letting kids know and kind of letting them explore on their time about their similarities to their peers and their differences. And overall, you know there's generally much more similarities than differences that kids have outside of just how they pee in the toilet and what their penis looks like. They like the same video games. They like different variations of video games.

Some people are smaller. Some people are taller. So really having that be kind of a key part kind of sets the stage for all of these things. And then talking about variation of the human condition within that. and how hypospadias or other urologic conditions are a variation of nature in many ways. And having that be the backbone of what we talk about.

So people vary in their interests, as we mentioned, and in their bodies. Highlighting that hypospadias is a medical variation, but again, also touching on the similarities. I don't like to, when I'm talking with a patient, similar to the pie example that was given earlier, I don't like to focus just on the differences. In fact, I like to focus a little bit more on the similarities as well, while acknowledging the differences, because the differences are important. And then kind of take a skill -based approach from that. And these skills for me fall into three buckets of skills that a kid could use when they're in the locker room or peeing behind a tree or whatever they're doing.

And the first approach is ignoring, walking away. Maybe using some nonverbals. Kids will often, you know, there's a phrase that a lot of kids use, adults, you don't want to feed the trolls. because you feed the trolls and the trolls get bigger and they're gonna keep coming back. So sometimes somebody says something to you that maybe you don't want to engage with, just kind of give them a look of like, strange question, maybe you're not saying it's just in your body language, and then go on with your day. So that's, that's one approach.

And none of these approaches are going to be the singular approach for every situation. But you want to build up a package of skills so that you can use them when the situation makes sense for it. So, ignoring walking away is one.

Deflection is another one. Again, these are all, you know, personality -specific and moment - specific. But for deflection, you might say something like, yeah, I had surgery when I was little and it's all good now. Just leave it at that, kind of nonchalant.

You don't want to make a big deal out of it. You're just like, okay, yeah, I had surgery as a little kid. It's all good. Then you walk away. If you give kind of like an elaborate big explanation, you're inviting more conversation, more focus, more teasing potentially.

Humor is another good one. Again, very personal to the person in the situation and how they want to deliver it. But maybe, you know, that high school boy who's in the locker room after football practice and his peers looking at him and wondering why, you know, it's looks a little different or why it's taking a little longer, you know, you might say, I don't know, man. Like, I think the bigger question is why are you so focused on my penis right now? You're just walking away. And I also think the third option is kind of a brief factual response and saying something like, hey, I was born with something called hypospadias and I had surgery as a baby for it. Again, with all of these not making like a really big deal about it, just kind of being like response, move on, not getting in a back and forth about it.

So, if you give again if you go in that back and forth, you might be reinforcing that teasing and then inviting more teasing, the trolls getting what they want. Then with all these groups so ignoring, humor, deflection, factual response. When the child's earlier this ties into the preparation. practicing these things at home. It might be, hey, let's role play what might happen. We're starting baseball season. You guys are going to shower together.

Let's practice what we might say. Or maybe something happens at school, and your son is, I don't know if I said the right thing. I don't know. OK, all good. Let's walk through what we could do next time. And just practicing in the safe environment of home when the emotions aren't high and we can kind of walk through it in different ways.

In a receptive you know family setting where it's we can try and we can jumble our words and it's okay we can practice with any skill practice is the way to get the skill better. And these responses to teasing are essentially skills. And I think also there's more like structural things that you can do as well. So in the locker room situation, maybe we change in the stall or we urinate in the stall just to avoid the eyes. Maybe we face the locker when we're changing, or maybe we wait till we get home till we shower.

There's responses we can do, and then there's ways that we can put our body in space differently to kind of mitigate as well. But I think with all of these, we want to avoid feeding the trolls. We want to give a neutral kind of response, not make a big deal out of it. just go on with our day. And then son comes home and maybe says, Hey, mom, you know, this happened. This is how I responded.

Parents role there is to really reinforce the positive behavior that you saw out of your son. I love the way that you did that. That was great. That was a really good response. So letting them feel good about it. So then they can replicate the behavior with further confidence in the future.

BONNIE: How much should our boys share with their friends? And how do we pick the people to trust?

JEFF GAROFANO, Ph.D.: This is something that in the bladder exstrophy world we work on a lot with kids, pretty intensely from when they're younger. Some of the principles with this one are, one is your son doesn't owe an explanation to anybody. They don't have to tell anybody if they don't want to. It's up to them.

You also want to open the door so if they want to, they feel comfortable and they can do it in a safe way. This is medical information you don't have to share if you don't want to and just letting that kind of be a safe place to land if they want. But then talking about who we want to, if we want to, you can kind of break that into tiers as well and you can kind of think of it as a three-tier level. You might have private people, so these are most people you might say, so kind of like the public having responses to them. They're the group of people that you might be least likely to share with. Then you have trusted friends, and then you have levels of trusted friends, BFFs, and good friends, and all of those things.

You want to start with who you trust the most to start with this. And generally, a good friend that you might want to share some of this with might be somebody who's just generally a respectful individual who you know you've maybe shared other types of information or secrets with before and they've been able to keep this information. So kind of somebody that's already demonstrated that they're not out there sharing your business everywhere and somebody that's probably also has kind of demonstrated that loyalty and that ability of keeping private information private over an extended period of time. So those are kind of the groups of people. And then in terms of like how to titrate the information, start with maybe like non-urologic small things and then just see how they hold on to this information. And if your friend shows that respect, kind of keep giving them a little more. And then all of a sudden, when you feel comfortable, then you can share it.

When you do share the stuff, framing it medically and confidently is really important. When we share, we don't have to give all the information. And then also you can mix in humor in there as well, if it's a close friend. Those are kind of the main ideas and it's ultimately your medical information, it's up to you. I do think disclosure can be important in many ways. I'm thinking of a patient that I had this week, who I wish had disclosed a little earlier, because now he's avoiding going to the bathroom when he's playing with friends in the afternoon all the time, and that's impacting his health.

If I had to err on the side of disclosure or non-disclosure, talking about things is important, but when the time's right, but also you don't have to. It's a delicate balance that'll unfold over time.

JENNIFER HANSEN-MOORE, Ph.D.: Yeah, I would agree with everything that you said completely. I think the way that we break it down in clinic just kind of simplistically, and really we, I share this with pretty much every family I see as sort of distinguishing between privacy and secrecy. So privacy is, you know, this is your information, this is your personal information, and it can be shared with whoever you think it should be shared with. does not need to be out in the wider world and shared with everyone without your permission.

But secrecy is really that feeling of I can't share this with anyone. I will be rejected. This is something that, again, it just kind of like links back to that to that feeling of shame. And so we want to avoid that. And so whether that is with parents who are wondering who to share this information with, how much information when the child is is an infant or a toddler or younger. And I think parents can sometimes go one of two ways.

They can make it very public and get support, but then in this age of social media, there is potentially something lost in terms of it being the child's medical information and wanting to protect that information. way and keep it private. But also I've seen parents who don't want to share the information with anyone. And then it leads to kind of other concerns like, well, I don't want my child to go to daycare because I don't want anyone doing diaper changes. I can't really leave the house if it's not my partner or I that's watching the baby because we don't want anyone to do a diaper change or give the child a bath or things like that. So I think it really depends on what role it will serve in sharing that information.

And definitely, we've seen that when a youth will share with one or two trusted friends that the psychosocial outcomes tend to be better, that they get to have that, because that experience of sharing with someone and then being heard and accepted is, again, that kind of antidote to shame. So I think it's really important. But again, it is important to choose who those people are and to be selective.

BONNIE: What are some of the healthiest coping strategies associated with the emotional aspects of hypospadias? And then how does one explain it to siblings in a supportive and protective way, intelligent way?

JEFF GAROFANO, Ph.D.: So yeah, so kind of tying into the other comments, you know, this is part of the patient's story. This is not the whole story, and it's probably a small part of the story, but an important part of the story. So continuing to grow those different interests, that self-identity, and to really reinforce those things while still acknowledging the differences. So then that ties into, we don't want to overly focus. We want to focus, but we don't want to hyper-focus on this.

And then for coping strategies know I like to go to cognitive strategies which are just thinking strategies. And, you know, I use a three-step process which I'm sure a lot of my colleagues use or some variation of. And when we're thinking about our thoughts, Our thoughts lead to our, are connected to our behaviors. It's all bi-directional. They're related to our moods, and these things kind of go back and forth. So, if we can change our perspective on how we think about things, that can often change how we feel and how we behave.

And a behavior in this case could be like disclosure. It could be going to medical appointments. Emotions could be anxiety, anger, all of those things. So that three-step process, again, this is not me, this is, you know, born out well in psychology, it's first noticing kind of the thoughts that you might have. And then when you notice those thoughts, rather than just the thoughts are just kind of going through your head and that's reality, that ability of kind of noticing that thought is really important because it makes it something that you can modify if you notice it. Then there's two questions that I usually have my patients explore. One of them is, Is this thought realistic? Second question is, is this thought helpful for me? So the initial thought might be, I'm never going to find a partner like this. I'm always going to have these physical concerns that are never going to get better. But then you ask yourself, hey, is this realistic? And is this helpful?

If you get a no for either of those, Then you go to the third part of it, which is trying to take a different perspective on how you're thinking about things, specifically a more helpful and more realistic perspective. So on the thought of I am never going to be able to find somebody that understands my medical condition. You thought, is it realistic and is it helpful, it's probably not realistic, it's probably not helpful. Okay, so a more realistic and more helpful thought might be, I think a lot of people have trouble establishing relationships and most relationships don't work out. And I might have to explain things that some people don't necessarily always have to explain, but I can work on that. And my partner may be accepting and they may not, but that's okay.

So that, you know, we're not lying to ourselves about the initial thought. but we're kind of helping to shape it to be more helpful and more realistic. And these thoughts, the thought modification or restructuring is something that very young children have trouble doing this, just developmentally normal, that this is a hard thing for children to reflect on their internal dialogue and their internal thoughts. But when a child starts eight, nine, 10, and then, you know, in the teenage years, that ability starts to be, to come more online and we could do that. And parents can model this as well for them.

Cognitive restructuring or changing our perspectives on things, so more helpful and more realistic, then that can lead to feeling better, less avoidance, more engagements, all the things that help. Then, you know, in terms of the body differences, just the understanding that bodies come all different ways. Everybody's got different things at different ages in their life, and that's normal. Some are short term, some are long term. Some have more heavier medical needs and some don't. And just kind of in a neutral way, just kind of normalizing differences can help.

So those are some of the broad things. Medical conditions don't necessarily happen in isolation as well. When we have thoughts and behaviors over time, these can often lead to things that are maybe even a little bit more. Being able to, for parents and for older individuals to kind of just notice, like, you know what, we might, we might need some help on this, or maybe I don't need need help, but I'm not quite sure. Maybe is there a counselor I can talk to? Is there a therapist I can talk to? And then kind of working through it.

So cognitive behavioral therapy is a great evidence -based approach for helping our mood, helping our relationships, helping our anxiety. increasing our engagement in doctor's appointments that can be applied to a whole host of things. parents modeling healthy coping in other ways, and then also parents noticing how their son is coping with other situations and applying it to the more urological situation at hand. So I think those are kind of some broad ideas about how we can cope, changing our perspectives, our behaviors, and then getting help when we need help.

When we're getting clinical help, I think earlier in the process, the better. We don't necessarily even have to have full-blown anxiety disorder or mood concern for psychological support to be helpful. Often, the sooner we can get in there and help, the better. So for a lot of our kids with bladder exstrophy, they might be doing fine. But I'll still meet with them maybe monthly just to make sure things keep going fine so that I have that therapeutic relationship so that when they do need help, I'm here, they know me and we can sift through whatever's going on with them. And then your second question was, it's how to explain it to siblings. All these things are family decisions and there's siblings are going to be of different ages. I generally think, though, like the earlier we can talk about this, the better. But it doesn't mean you have to talk about this like right off the bat either. And when you do talk about it, talking about it in kind of a medical way again is really important. So, you know, your brother was born with a medical condition where it

changed where the opening of his penis was. it's in a different place and the doctor's fixed it, or he's going to a doctor's appointment so they can work on it a little bit more.

And just keeping it kind of like neutral, it's a medical appointment, and then you can relate it to maybe a medical appointment that the sibling had for another condition. Bodies develop differently, that's important to talk about. And then also really teaching siblings that we're in a family, so we're talking about these things, But this is your brother's information, and we should keep it generally within the family. If your brother wants to share, that's OK at an early age. And then also really building up camaraderie between siblings. So, when one sibling might be going through a tougher time, the other siblings are there to help.

The other siblings might be there to defend in some ways if they feel like they need to, not necessarily physically, but there to help and that they're looking out for each other as a family. Those are some of the main ideas.

BONNIE: *The hosts of this podcast are not medical professionals and the information presented during the podcast is not intended as a substitute for medical advice. If you or someone you love has a medical question concerning hypospadias, please consult your physician. For more information related to this podcast, visit livingwithhypospadias.com*.

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