HYPOSPADIAS CONVERSATIONS

TRANSCRIPT: DOCTOR'S ROUNDTABLE PART 2

Episode 16: Discussion with Doctors: Vinaya Bhatia, MD, Lauren Corona, MD, Pankaj Dangle, MD, Christopher Long, MD, Hadley Wood, MD

***JOHN**: Welcome to **Hypospadias Conversations** with cohosts Bonnie Steinberg and John Filippelli. We are members of the community that have experienced living with hypospadias, epispadias, the surgeries that are often used to correct for them, and we want to talk to people who are members of that community and their family and friends about many of the feelings and issues that we all have faced. We are not doctors we do not represent the medical community and we want to be clear that we are discussing our personal experiences—experiences that too often are not shared, leaving many boys, men and families feeling that they are alone. You are not alone. Our goal is to offer frank conversations about our thoughts, give many people company, give parents who are wondering what to do with their new babies that have been born with hypospadias or epispadias, some resources. to think about treatment. To think about parenting boys with this difference. The conversations are personal, frank, and we hope that you are aware of how vulnerable we feel, how risky it feels to open ourselves up in public. We hope to cultivate your compassion and understanding and create more safety to have these conversations.*

JOHN: In our discussion with other guests over the years, we've found a number of men who had never been told by their parents that they ever had repair surgery as a baby. And if you could, please talk about the importance of parents discussing their child's surgical history with them so that they're informed should they need care as an adult in the future.

DR. BHATIA: I'll start here, although all of my colleagues have great experience to share on this question. So we actually interviewed five to 50 year olds with hypospadias to kind of understand their care experiences, their care needs, and what the process of understanding their condition was like. And truthfully, the majority of my patients under the age of 11, their first disclosure was the interview with me. That was when they found out they had surgery.

And so I think one thing that we encountered as we were kind of developing our support tool, our long-term care planning tool, was that a lot of families were asking for discussion aids to say, 'how do I open this discussion with my child when they're five, when they're eight, when they're 10? How do I tell them what they need to be looking out for as they reach adulthood? Because I don't know how to start that conversation.' And I think we're gonna have some of our other colleagues address how and when they get psychology involved and also how they take health literacy into account. So I'll let my colleagues hop in now.

DR. DANGLE: I think that's been a challenge for all of us in many aspects of clinical care. If there are no complication, it's great. But if there are complications, then there are many aspects of psychological trauma [these] boys go through. And we just recently—and we are going to present our data at AUA and talk about that—is we're doing a phone survey. And just to address the issue, what Vinaya just talked about is, many of these families or the patients did not know what their diagnosis or what surgery [they] had. So to be in the legal bounds, we actually contacted their parents. And out of four, five hundred phone calls, we were able to get 80 patients to answer our survey, which is quite a lot of number, if you can see that, is so many patients did not know what their primary diagnosis was, because we didn't want to get into a situation where you reach out to the patient directly, even though they're 18 and adult by definition, to have the repercussions of why did you reach out to my child without my permission.

And that's what's very striking to me is, what is that barrier that the families or the parents are facing to kind of open up this discussion about the child's care or surgery to their boys. Maybe it's because it's a surgery on the penis and that could be taken as a many societal acceptance of how and why it should be done. So I've changed my practice over the years in trying to ask the families, would they be sharing it? And at what age? And how? And if the answer is no, and what are the barriers that they face typically in trying to open up this conversation with their children? And we are reaching out to many families who had kind of lost to follow up and offering them to meet with us and kind of discuss openly with the patient and the family and answer any questions, concerns that they might have. So again, another 10, 20 years before we'll understand many aspects of this shared decision between the families and the child in terms of their previous diagnosis.

DR. CORONA: Yeah. So, I've had the same experience in my practice, and I don't know where the breakdown happens. Is it that we're failing to emphasize the importance of disclosure? Is it that the families want to disclose and don't feel like they're empowered to do so? Is it that they feel like they don't want to? I guess overall, it probably why it happens isn't as important as how we can correct it.

But I know that I'm embarrassed to say that I recall a visit early, I'm still early in my career, but very early in my career when a young mother came in with her newborn son and asked, “Is he ever gonna know about this?” And when I asked her why she was asking that question, she said, "'Cause I don't want him to, I don't want him to develop a complex." And I know that I didn't have the words in that moment that I wish I'd had at that visit to help that mother understand that knowing about his body and his medical history doesn't create a complex, but the secrecy and the unexpected discovery of that certainly might.

And certainly we can't force anyone to take action there, but I think I definitely could have done a better job of making sure that she understood why I think it was important that she does and why it mattered. And if I've had this experience, I'm sure I'm probably not alone in having others having experiences like this.

And you spend seven years getting to this point as a new attending urology residency, then you do an extra two years of pediatric urology fellowship, and you're in the operating room almost every day and you have so much to learn from a technical standpoint. There's that saying that proper preparation prevents poor performance and that's really honed in on us from a technical standpoint. But there are all these extra soft skills and all of, you know, these important components to counseling patients and families that if you're not practicing them in your training, they're not going to become natural to you to do when you're speaking with families.

So, I think equipping us surgeons with the language to be able to do that well is really important. So, I love the work that Vanaya is doing with the discussion guide. I think something like that will be really helpful. But I think making, also just giving us the knowledge and the words to be able to talk to families about this importance and making sure that sharing this information in an open and age-appropriate way will empower their child, not harm them, that the child will take cues from the parents that if they, you know, present things as facts and this is how it is, then it's much more likely to be accepted without distress, rather than doing the opposite, which will make them feel shameful. And then really making sure that they know that this is his body, this is his story, and it's really his right to know.

And I think if we can convey those things to the families, then we're going to set the parents up for success in that regard. And I think also figuring out how to bridge that long gap that can often happen before this disclosure is going to happen is really important. So, I love the work that my colleagues are doing in this regard.

BONNIE: In the olden days, physicians told parents not to discuss this with their kids because the surgery would be so successful that the kid would never need to know. And that kids, babies, you know, heal so resiliently that they'll be fine. So, we were caught by surprise when there were complications and the kid was older and the surgeries had different outcomes than what we were told in the beginning. So that history is still present.

And I think that you guys are kind of the vanguard of trying to move the movement forward.

DR BHATIA: And I will mention here, we have some forthcoming studies on the psychological impact of surgery, care received, counseling, experiences with clinicians and nurses. And one theme that kind of carried through every stage of development was avoidance of disclosure and really related to a sense of uncertainty. Uncertainty about what it meant for their future, uncertainty of how it affected their ability to relate to their peers. And so, I think we are seeing the why, you know, and talking to our families from a very early age to kind of support the idea that as Dr. Corona said, you know, avoiding disclosure is not going to help them know how to understand their body or voice their concerns in a healthy and balanced way. And it's not going to help us take good care of them, because what if they don't disclose concerns to us, right? And that's really, it's a double-edged sword for in a lot of ways.

So just one kind of additional piece that related to what you expressed.

DR DANGLE: I agree with everything you just said. I think the world is moving in a different direction in terms of connecting with each other with social media. And certainly children who had these complex surgeries or any complex medical condition, there is a lot to learn from each other and kind of helps so you don't want them to have a disclosure from a social media which says through a proper channel be the parents or be the provider. And just to go back to some of the previous questions and concerns I think the biggest challenge the parents or the young parents have is whenever there is a phallic anomaly or something like a hypospadias, these parents are concerned about the long-term sexual and psychological impact more than anything, and the fertility potential in this kid. So, they may not say it, but it's there in the back of their mind.

I think as providers we should be a little more forthcoming about what it means to have a hypospadias and does it impact your fertility and do you have to tease those topics out individually for them to understand, no, your fertility is fine. Yes, you [are] going to have issues or challenges with psychological as well as sexual outcomes and we have to focus on individual aspect of it and kind of prepare them on why it is important to have the disclosure with this boys and at what appropriate phase of life and be part of it when it is necessary to do so.

JOHN: Dr. Long, we understand you have a psychology assistance program to educate parents to disclose his right to know. Would you be able to talk to us a little bit about that and the importance of it?

DR. LONG: Of course. So, you know, I've had that conversation with families, you know, they kind of ask, you know, when do we disclose this? How do we do it? And I think, I think it's an interesting question. Right. So I think that every parent approaches it differently. I think every patient is able to respond to it differently.

In the end, in the long run, my preference and what I use to convey to families is I do think it's very important to disclose it to your child. Number one, just because I think it's important to know that there was something that happened there. And even if you just say, hey, you had surgery, everything looks perfect, you know, there's really nothing to worry about. But just so you know, you did have surgery there. It does make a difference because there can be a medical procedure later on in life that they might get that's going to be really important. They might need to disclose that to someone because otherwise they could get injured, that repair could be injured, and then you could have a big issue on your hands. We do have two psychologists on our team and they're invaluable in terms of dealing with many of the issues that we have with some of our patients that—you know, we're trained as surgeons, and I do think that it's important to sort of get that emotional component, and they have a unique connection with families and patients.

And so, you know, what we do is we try to sort of get them in, and we try to identify maybe families that might need an extra conversation or the patients that might need a little bit

more coping strategies to go through it, we'll bring them in and have them discuss and consult with the families. So I do think that they are a valuable part of our team. And I think that, like I said, I think they can direct things a little bit more age appropriate in the conversations because they've had so much more training that we have in terms of connecting with families on that regard.

BONNIE: When do you believe hypospadias repair surgery is the correct intervention for a pediatric patient or then for an adult patient?

DR. LONG: So, I think that's a good question. I think the conversations that I have with families in terms of something that might push them more towards doing surgery in the pediatric period would be if we think there's gonna be a significant detriment to them in terms of function. So we always—I always break it down in terms of urinary function, sexual function, and then appearance, right? I mean, I think that, you know, that is something that families and adult patients, adult males, do want to consider as well in terms of the appearance of the penis. But primarily focusing on function, particularly if the urethral meatus, even if it is pretty distal, it's close to the tip of the penis, if it is very narrow, we've seen patients where over time, it might not be something where you noticed it initially, but, you know, maybe 10 years down the road, 15 years down the road, they can actually get—just because of that constant urine going past a narrow area can increase the pressure of urination. It can actually cause scar tissue around the urethral opening. It can actually lead to a lot of scar tissue in the urethra itself, even if they've never had surgery. For me, that is something that's very important to convey to families. If we see that particular variant on anatomy, that we need to address that.

I think penile curvature is another one. In terms of comparing the adult literature on the significant impact of curvature. Around 30 degrees or so is the dividing line, as best we can tell, and what I sort of convey to families. And if it's over 30 degrees, then I think that that can have a significant impact on sexual function, happiness with their outcome as they're older, and so it might drive someone more towards surgery if we see that.

Now, adult-wise, I think—you know, Dr. Bhatia was there, but, you know, in Las Vegas, we had our annual meeting, and there was a lecture given by myself and Dr. Gonzales from Loyola. He's an adult urologist, and we were sort of comparing different clinical questions in terms of, like, age for fixing hypospadias. do we want to do this during the pediatric time or in the adult time? And Dr. Bhatia was actually the moderator there. So she came up with some great clinical scenarios for that.

And so, I think the bottom line message there was—you really want to ask the patient, you know? I mean, I think there might be a situation where I might look at a patient and I think that this is something that really needs to be fixed and if it was me, then I would want to have that repaired. But the patients might not want to do that. You know, I think the curvature that they may have might be functional. You know, they might not mind if the urine sprays a little bit. They might not mind sitting down to pee.

However, they also might have a very minor abnormality and they want it fixed no matter what. And so I think my job in terms of talking to patients and families is we can do the surgery, we'll go through in terms of, you know, what we think the outcomes will be and what will be safe and ultimately leave the decision to them, whether that's the parent or whether that's the patient. And I think, you know, especially the older patients, a lot of times it's more than one surgery. And, you know, sometimes we have to use grafts in order to achieve that. And like I said earlier, I do think that the sort of recovery process, how they experience pain and the catheters, I think is much different than it is for the younger patients. And so that for sure has to factor into that for them in terms of whether or not they want to go through surgery.

And so, I would say that I'm brutally honest with them very upfront in terms of what to expect in terms of if they do go with surgery and if they don't go with surgery, and we have a conversation from there.

DR. WOOD: Well, that's an interesting question because I, full disclosure, I do not do pediatric repairs, so I'm never interacting with children. It's generally recommended that it be done sort of quite young, you know, around the age of 12 or 18 months, depending on other health issues and access to care and that sort of thing. And I do think that the children that have it done before they can form memories of it tend to do better.

The problem is, is that some young—some young children have a repair and then they have a complication from that and then they have another complication and the repairs extend into elementary school age and maybe even beyond and that can be quite traumatic. I see a good number of young men who verbalize, you know, trauma experiences, having catheters removed, having the urethra dilated, having procedures done that they didn't want to consent to or being held down for a procedure. And so, I know some of that really sticks with these young men.

And I think there's a little bit of a changing paradigm, definitely depending on what culture or context you're in about maybe distal hypospadias that might not be associated with a ton of curvature to sort of leave that be and let the young person decide when he gets to an age where he can understand you know and appreciate what surgery would be. I don't know what that age is, you know if it's at the age of ascent which is typically around you know age 11 or at the age of ascent, which is typically around, you know, age 11, or at the age of consent, which is 18.

So, I think things are changing a little bit. And certainly in Europe, you know, wholesale operation and everybody with hypospadias is not the norm. It's usually just patients with pretty severe curvature or more proximal forms of the disease.

DR DANGLE: I think most of us would agree that in a healthy baby boy who is a full-term—surgery within the first year of life is important because not only they, as you said, Bonnie, that they are resilient, they heal really well. And the trauma from the surgery and the anesthesia and the parental suppression does not last long. We all have been in a situation

where we've done surgeries at a younger age and these kids are thriving within a day or two and have no recollection of what was done, versus a kid who is between like two and a five which is extremely difficult for them to go through any kind of intervention that may be separating them from parents. Penile surgery becomes more and more challenging. So, I tend to lean on the side of younger age but again you have to make that decision based on individual patient and the families.

I've seen in my practice, as our census data is changing, more and more patients are getting referred to us or seeking help at a later age, which becomes more challenging because we're seeing more and more older kids with the primary diagnosis of hypospadias seeing us at the first time or seek asylum in the States and have either complications or different phases of surgery, which they need to be done.

And as far as adult, I think we have to be mindful of having that access to these families or these patients as when I was talking about the aid and connecting with the proper resources when they are adult to deal with the challenges or any complications if they face later in life. And that's the challenge they face, is they don't know where to go to and we learned that from our survey is that though these patients have [these] concerns about what's going on with their body image or functionality, they don't know where to go to. And that's the big issue that we need to kind of help them guide through. And as Dr. Bhatia is doing phenomenal work that will help a lot of these young men.

DR. BHATIA: I should mention that Dr. Dengle has been helping me extensively at this project, so he is just as much a part of it as I am. But I think we are still figuring out who really needs early surgery and who can afford to wait without suffering worse complications. There are some criteria that are starting to come out in the adult literature about significant curvature being very challenging to correct in older patients. It can be important to correct that earlier because then you set the patient on a appropriate course for straight growth over time versus having to kind of claw back the problems that have occurred because of scar tissue that was never addressed.

Other things that have come out in the adult literature, and I think Dr. Wood is going to talk about this more, you know, severe stenosis, obviously a more proximal location, the outcomes they're seeing for delayed surgery in adulthood are possibly even more complex than what we're seeing in an early pediatric setting.

But this is not an emergency surgery. This is a functional surgery for quality of life. Every patient is different. Every family is different. The care that they're able to support is different, right? And so, it's our job now to really work with a multidisciplinary team and contextualize—help the patient contextualize the decision and understand what they're getting into. And so, I think the counseling piece is intrinsic to deciding on the correct timing of intervention for each patient.

It's super individualized, right? It's not a panacea, it's not an algorithm. And I think that there's a lot of literature on, you know, we have no guidelines for care of hypospadias.

That's because every patient deserves their own kind of personalized plan of care, right? I think saying that you can be algorithmic about it limits our ability to really help our patients to the best of our ability.

DR. CORONA: Yeah, I don't have a lot to add other than, you know, it should be performed when the family is ready for it to be performed and when the family has made that decision for their son. It should never be a decision that's made for them. But once they've heard everything that was just discussed and feel that they think that that's the best course of action for their child, then I would recommend it. And if that time course happens to be in that 6 to 12-month age range, that is an optimal age range to fix it.

JOHN: And Dr. Bhatia's answer kind of led me into the next question. So she covered a little bit of it in terms of criteria, cosmetically and functionally. Is there anything the panel would like to mention about that in terms of what are some criteria for a successful hypospadias repair?

DR. DANGLE: I think setting up the goals before the surgery of why is important with the families. Having them understand the different aspects of surgery and why they're done, and when to do the surgery, when not to do the surgery is also important because not every hypospadias needs a surgery. There are some hypospadias which are almost near normal and functionally would not benefit from any surgical intervention. I would explain to families why it is not necessary for this child to have a surgery for anything, if necessary.

And for me and having the families understand that is very important. I try to focus on individual aspects of the outcome, be it urinary, again, the psychological impact, the sexual, and then the overall cosmetic appearance. I try to go through each piece individually with the families. Again, the discussion will change when you're talking about more common variety of distal hypospadias versus the proximal.

And I feel like even the distal hypospadias, every family is different because every geographic area is different. Our practice here in Indiana is a lot of rural America, kid with a little catheter home, when that caregiver is working, you know, the job, et cetera, et cetera. So, how do you find that balance and trying to come up with a solution which will help the patient and the caregiver at the same time? So, over time, I've learned to get into—dig deeper into these issues to make sure that I understand what challenges they're going to face and not just put it on them as if it is their issue and not my issue. So very important to connect individually with everyone and try to get to that balance between the optimum care and when and how, as Dr. Bhatia just mentioned, is it has to be patient-based.

For me, the more complex hypospadias, I like to see them at least a few times before putting them through the surgery and making sure that they understand. So it's, for me, it's like a homework for them, is, 'do you remember what we talked last time' and then we make notes together and everything which they say which is you know close to being what was discussed in the past meeting they get a checkbox and what has been missed we go through it again and then we meet again before we make the plan of surgery and then we go through

the plan of surgery of how we're going to do what to expect and how many surgeries or interventions is going to need at what interval phase of life and what challenges emotional or stressors it's going to be for the child. Setting up those goals and expectations with the family forefront is very, very helpful. They trust you right away from the door. And when being honest again, I just keep coming back to the honesty is so—such a key in this particular aspect of the child's care. Not that the other aspects of medicine are less important, but this is very impactful for that boy.

JOHN: It sounds very much like it's very much a working relationship between you and the patient as well.

DR. DANGLE: Very true. The trust is the key in anything, but very, very important in those proximal hypos.

DR. BHATIA: I think, you know, you're right that I alluded to some of the definition of success in the previous answer. It is a quality of life surgery, and so the success should be from the patient's perspective. There have been a lot of studies looking at cosmetic concordance in terms of satisfaction between the surgeon and the family, the surgeon, the parent and the child or the surgeon and the adult patient and the concordance is variable, you know?

So, I think ultimately the person that is using the surgical site is the person that should be commenting on how happy they are with it. And so we are trying to define patient-specific criteria for success, again, with our clinical tool, right? So, if a patient says that they're happy with their stream and they're not having signs of problems that we would consider clinically impactful, like God forbid kidney failure or bladder outlet obstruction type symptoms, everything else is okay, then that is the barometer of success that we're gonna be going off of. And I think that I am not unique in this perspective. This is something that is kind of coming into the ethos for pediatric urologists around the globe and definitely in the United States.

DR. CORONA: Yeah, so, I would echo what my colleagues have said already and just say that, you know, success is determined by the patient. I love how Vinaya put that, the user of the surgical site. So it's important for us that are performing these surgeries to figure out what success means to a patient and what's meaningful to them.

Our discussion will continue with part 3…

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