HYPOSPADIAS CONVERSATIONS

TRANSCRIPT: INTERVIEW WITH DR. HAZEM MOSA

Episode 11: First Segment in a Special Multi-Part Series with Dr. Hazem Mosa

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.

JOHN: Welcome to another episode of Hypospadias Conversations. I'm your host, John Filippelli, along with my co-host, Bonnie Steinberg. How are you today, Bonnie?

BONNIE: Doing well, glad to have this conversation.

JOHN: Definitely, definitely. And we're both very excited and honored with our guest today. Dr. Hazem Mosa is a senior fellow in pediatric urology. He trained in pediatric surgery at Alexandria University in Egypt. He trained in pediatric urology at Guy's and St. Thomas' Hospital and Great Ormond Street Hospital for Children in London, England. He currently works in Cambridge University Hospital and his research on hypospadias has been presented in international conferences and published in peer-reviewed journals. He serves as a reviewer for multiple scientific journals to assess the eligibility of research articles for publication. His research focuses on hypospadias surgery complications, informed consent, and parental decision making in hypospadias surgery. Welcome Dr. Mosa.

DR. MOSA: Thank you, thank you. It's a pleasure to meet you guys. It was really interesting to find the podcast through the Hypospadias Epispadias Association and I was so glad such a resource exists out there for parents.

JOHN: Well, thank you.

BONNIE: Thank you.

JOHN: I think the first question that I have and I think that most people are going to be really eager to hear your answer on is why is informed consent so important especially in the area of hypospadias?

DR. MOSA: I think with everything we do in surgery a really integral part to a patient's autonomy is informed consent, because each patient or each parent in the case of children's surgery is entitled to make decisions about their health. And there isn't that universal assumption that your doctor knows best and they get to decide. The decision always has to be in your hands. And part of that process of enabling you to make that decision is an informed consent. You need to know what surgery you're having, why you're having it, and most importantly, part of the informed consent process is what happens, what if you don't have a procedure? What's the outlook of life without surgery?

JOHN: Right, and I know you talked a lot about preoperative counseling as well, so I would imagine that those types of topics are introduced at that point.

DR. MOSA: Of course, well, I think that there's always a kind of widespread belief that consent for surgery is something to do with signing a legal document on the day of surgery. But that's not entirely true because the process of getting someone to make such a big decision starts early on, it starts way before the day of surgery. It's when you first meet your urologist in the office, sometimes that takes a few visits, a few hours of conversations to kind of walk through the process of consent. So, it's not just you signing a legal document on the day of surgery to agree to the likelihood of complications. Many people think that that's consent. Consent actually is a much more complex process, and especially when it's to do with hypospadias, where there is controversy about when to have the repair, what repairs to have, and what hypospadias you're dealing with, a longer time for conversation, a longer time for a parent or a patient to do their own independent research before coming to a conclusion. Simply saying this is a done deal, this is the operation you need to have, we'll see you on the operation day, you sign a consent form on operation day and you have a list of complications to agree to.

I don't think that's—what we want is an informed consent that generally involves at least two visits before making the decision for an operation. So most people would see their urologist soon after birth once the pediatrician or a neonatologist have made the diagnosis and referred them. They'll say something along the lines of, well, this is nothing to worry about for now. You'll meet a urologist, and then that's going to be an easy fix or a quick fix. So, it's what that's the first kind of encounter where you meet a urologist where, you know, the assessment is made is this distal hypospadias.

So, for the listeners, you know, broadly, there is distal and proximal hypospadias. Proximal is the more severe form of hypospadias. And generally, that's the type where there is curvature of the penis, it's more difficult, more demanding to repair, generally associated with more complications.

So, the first visit is the exploration of what we're actually dealing with, and then based on certain criteria, do we think this can be repaired, *needs* to be repaired, or is there a choice to be made? And then after that initial encounter, generally parents shouldn't feel obliged to make a decision on the spot. You'd need your time for independent research, you need your time, you know, to seek other resources, parent perspectives, older men who've had surgery, and then a second meeting or a second consultation is the time where you've got your questions to ask and that's, you know, what kind of surgery will it be, how many operations are we expecting, what's the likelihood of complication, what's the long-term outcomes going to be, and then that's where some parents would still need the further consultation to reach the final decision. But always, you know, the day of surgery is generally to me the *third* opportunity for someone to discuss their worries or if they've got questions. So in my view, that's the general outline of going through the process or discussing what surgery involves on these three occasions. The initial soon after birth, you've had a reasonable time between soon after birth and, you know, six months of age where generally most people would meet and schedule surgery and then between the scheduling of surgery and the actual day of surgery which is again there's going to be a few months.

BONNIE: For shared decision-making I think the ideal has been to have a team, not just the urologist or surgeon, but to have a real wide team of people to answer questions and present the kind of information that parents need. Are there any centers that have that kind of team with a process for parents?

DR. MOSA: In the NHS in England, we're quite fortunate to kind of have access to that. And especially, this is going to be more accessible to someone with proximal hypospadias or severe hypospadias. So being referred to a dedicated clinic where you'd see a urologist, an endocrinologist, a psychologist, there'll be a wider team that helps you make decisions. There'll be a geneticist for genetic counseling and genetic testing if you need it. But generally, for distal hypospadias, that wouldn't be the case. It would be meeting a urologist. And generally, because we—with distal hypospadias, the likelihood of an underlying genetic abnormality or other endocrinological problem is always thought of as a isolated genital problem rather than a more complex endocrinological etiology. And to be honest, in proximal hypospadias, the majority of boys will also, who undergo testing, will have normal testing, but it just helps answer these questions for the parent. There is always comorbidities, there is undescended testicles that can happen with hypospadias, especially proximal hypospadias, and that has more endocrinological and genetic implications than just having hypospadias. But we're quite fortunate to be able to offer that MDT approach, the multidisciplinary team approach, to those with more proximal hypospadias.

BONNIE: So proximal is the more difficult, distal, so-called easier. What do surgeons say to each other about the complications? You call the complications the elephant in the room. And what do surgeons say to the parents and potential teenage or adult patients about complications?

DR. MOSA: I think complications in hypospadias is such an area where there is such huge discrepancy between what the non-specialist informs the public and between the actual reality of publication and science. If you look—I was enjoying listening to the podcast where you'd spoken to the parent of a child with hypospadias and she narrates a typical parent's journey with hypospadias when, you know, your boy is born and someone tells you they've got hypospadias, don't worry, a urologist will fix it, you'll meet them later. And then she goes on to talk about what happens with complications and multiple reoperations and nowhere in the beginning of that journey that is disclosed to mom. It's always kind of been—and if you think about the pediatrician who, in good faith, gave that statement that, well, this is okay, this happens all the time, and urologists fix it all the time. They say that in good faith because that's what institutional publications or parent information leaflets tell parents.

And we've actually presented that in the Hypospadias International Society in 2021 when we looked at all the parent information that's out there in the English language and that's just using Google as the most widely used search engine to see what do parents have access to. And we've, you know, ruled out any paid advertisement, we've ruled out anything that didn't come from a reputable institution that should be the authority to tell parents what to expect. And the majority of these publications don't really address complications in the way that would you know, worry the parent or make them aware that there is a decision, that the decision to be made does involve a lot of complications. If you look at something like a proximal hypospadias where world-class institutions have published complications rate as high as 50% and 80%, you really don't find that disclosed in the same institution, parent information leaflet, if you look, if you take out just an institution that has published their data to say long-term outcomes, we've had 50 or 80 percent complications. But then look at the patient information leaflet that will say, you know, some patients experience complications and they're easy to fix. We would fix them. We're an expert in doing this. We do—we see a thousand patients with hypospadias a year to kind of say you're in safe hands. We do this all the time. Don't worry about complication. But the actual reality of the complication rate of experience is really high. So, I don't find that there is a true reflection in the published information leaflet that's out there.

Again, one of the things that the mum of that child with hypospadias talked about is I went out there to look who's the best surgeon, who can do this best. And if you go to the internet and you find, you know, a center of excellence or a place where you associate with excellence or your paediatrician tells you where the really good urologist is there and you find a leaflet that's addressed to you and it's just in quite simple language that says, you know, everything's probably going to be okay, but sometimes it's not, without really disclosing. One thing we specifically looked at, do you disclose a percentage for complications? Because that's what every parent comes to the office wants to know, when you say, well, there's likelihood of complications, but you don't have to worry. So they'll say, well how likely are the complications because they'd like to hear a number.

And the majority of urologists won't have individual numbers or individual data. They wouldn't have had any inquiry into their own results, which is really quite surprising and shocking because of how high the complications are in hypospadias. You would expect anyone you see would have a personal record of how likely the success is, but that's not the case. So you'll be quoted arbitrary numbers or, you know, a figure out of the literature of a systematic review, for example, of many publications to say, well, there is some complications.

But it's an integral part to the informed consent process I find, is being able to quantify risk because everyone assesses risk and benefit differently. Every parent, some parents for example, would be worried about a general anesthetic more than anything else. So they'd like to avoid a general anesthetic at all costs and that's up to them. That's just, it comes to your personal experiences, you know, things that happened in life. How you make a decision is up to you, but you need to have clear information to help you make that decision. And the key thing is going to always be what is the likelihood of complications, which what adds to the complexity in hypospadias, but that differs widely from center to center, from surgeon to surgeon within the same center. And that's the key problem. And whenever you try and present a resource for parents, this number is always going to be changeable. There isn't the number that you can safely say, this is the likelihood of complication, no matter where in the country you go and have surgery.

BONNIE: I'm sort of overwhelmed by the idea that at a center of excellence, and we know this from fact, the complication rate is 50 to 80%. The sequel question, the next question is, once you have a complication, what are the options and how long in your life do you have it? And many of the surgeons know that there are reports from men who have these complications for life, and they worsen over the decades. And the repairs over the decades are as complicated as the original surgeries, but nobody predicts that for them, tells them. It's kind of unpredictable who's going to fall in the 50 to 80 percent, but nobody has long-range studies. They have studies of three months, two years. five years But, they're not talking to the men who are in their 40s, 50s and 60s to find out how things went Or what they've learned to live with so the complication question is a huge as you say elephant in the room So I don't know how to follow up on that. I'm just stunned by the continued lack of people owning up to that. I guess we really hope that doctors are honest. So, I don't know what the question is. I guess the the next question just is again what do surgeons say to each other about these complications and why are they not more forthcoming and why are they not more interested in truly long-range outcome studies, studies over the decades of a man's life?

DR. MOSA: I think one thing that was quite surprising when these studies came out, because it had been, you know, previous studies that will quote lower complications rate from the same institutions, but then when they've had slightly longer-term outcomes and reported these complications, we thought the response would be, well actually if we've got this high of a complication rate, something needs to change. You know, whether it's technique, whether it's who gets to do these operations, because we know that if you specialize [in] surgery, if you get fewer people to do the surgery, you get better outcomes and to my surprise, there was within the wider community of more of an acceptance of a higher complication rates if you if you work at the Hospital that's maybe not associated as being a center of excellence and you say well if these guys have a 50 to 80 percent complications, then who am I to have a better outcome?

And there was sort of kind of an acceptance to say, well, it's proximal hypospadias, has high complications, take it or leave it. Of course, there's always outliers that you can see in publications where you get an exceptionally lower complication rate. But the response always to these centers that have that low complication rate is, well, this is kind of your thing. Everyone else is just going through complication, rather than saying, well, what are you doing different to get low complications so we can change?

We know publications, from Bush and Snodgrass have published some of the lowest complication rates in hypospadias literature. We know some of the results published by

Professor Peter Cuckow from Great Ormond Street have had some of the lowest complication rates in the literature, but it's never the response to these is never what are you doing different so we can change to get lower complication. The kind of it's—because it's an uncomfortable truth to say if other surgeons can get better outcomes, then there must be a problem with the way we do surgery and it's not something easy for people to admit that there are complications and they—there is something to be done to change. If you accept the reality that well proximal hypospadias just means more complications you just have to be be prepared for that. But that's not true because we know other centers *can* produce repairs of the most severe forms of hypospadias with excellent outcomes.
There is actually a phenomenon in hypospadias and really well-done hypospadias repairs, an ethical problem of disclosure. Do you ever tell your child that they ever have hypospadias. That's how well surgery works. You have surgery before two years of age, you have a completely normal looking penis, you don't have any urinary problems, that parents would come and say do we have to disclose to our child that he ever had hypospadias? Is this something we need to tell our child? So, there is a spectrum, there's a spectrum at one end where you've got—which is more common than we'd like—is high rate of complications, long-term suffering, a long-term journey when you're in your forties and still having reoperations. You've got the other end of the spectrum when you've had surgery when you're less than two years of age and you just never had to talk about it ever again, which I think is generally what parents expect or want you to say when they come, when they come to you with hypospadias, what they would like to know or would like to hear is once this is fixed will we ever have to worry about this again and that should be the standard that should be where you're aiming rather than settling for well if a center of excellence has published poor results then we're all equally allowed to have poor results.

JOHN: I wonder too Dr. Mosa you have such a unique background that in your experience have you noticed is there a cultural difference uh... say from the east and the west in terms of how this is all handled do you see certain areas this is for the benefit of those listening that might be from different parts of the world uh... what a parent can expect or what I guess, standards that you're seeing as far as this sharing of information uh... is there differences?

DR. MOSA: I think there are there are differences and even within the west, especially in the UK, again we're privileged to have the NHS where every child anywhere in the country gets any surgery they need free of charge, no questions asked, that's kind of the basic premise of the NHS, nothing to do with payment, nothing to do with insurance, and again, nothing to do with bias, you know, if you go to a surgeon it's just your best interest is kind of implied, because no one is trying to get you to have surgery it's there is freedom of choice in a way for you to make a decision and in the UK especially that has led to kind of many government led initiatives that can facilitate better outcomes, because again surgery is not incentivized by money. No one makes surgery [money] by making more surgeries. So it's always going to be do parents wish to have surgery? And if they do, how can we get the best outcome using the service we have? That's why we have an initiative in the UK that's called 'Getting it right the first time,' and that's for a lot of childhood surgical procedures but mainly a big part of that initiative is hypospadias and that looks at individual outcomes from each hospital that provides hypospadias surgery, what's your complications rate and that is meant to monitor case volume, how much hypospadias operating you do, and do you get equally good outcomes? And we know that higher volume centers tend to get better outcomes because of the accumulated experience.

Also specific to the UK, there's something that's slightly related to hypospadias, but not quite the same, epispadias, which is part of another abnormality that's called bladder exstrophy, which is the bladder being on the outside of the abdominal wall that's associated with a defect of the penis, the epispadias, where the opening is on the top of the penis rather than the underside of the penis. And in the UK, because of, again, outcomes that surgery for epispadias is centralized to only two hospitals. So only two hospitals in the UK by law are allowed to operate on patients with epispadias and that the driver for that is getting better outcomes because we found that epispadias again is much rarer than hypospadias and bladder exstrophy is quite rare as well and that's about one in 37,000 as compared to hypospadias. So, when you look at centers in the UK pre-centralization each hospital was doing one repair a year and you can't be good in anything that you do once a year. It doesn't matter how good of a surgeon you are if you're doing an operation once a year you just can't be good at it. And that was a driver for centralization where you get Great Ormond Street Hospital and Manchester and these are the only two hospitals allowed to carry out the operation. So if you're born anywhere in the country you will just get your surgery done in these two hospitals and that just maintained high quality outcomes and that actually came on the back of another centralization initiative.

So, the first ever operation to be centralized in the UK was called biliary atresia, disease of the liver where children are born with a problem in the connections of the bile ducts that drains the bile from the liver and they get jaundice. They require a complicated surgical procedure to relieve the jaundice and sometimes they require liver transplants. And the reason that had driven the centralization of biliary atresia in the UK was parents. So parent pressure groups. And mom, again, it's compared to hypospadias, biliary atresias has got kind of consequences of mortality. If you, you know, if your operation fails, you just, you don't simply have another surgery, you just die. And a parent who sadly suffered the death of their child after an operation being done in one of the low-volume centers started a group, the [Children's] Liver Disease Foundation, and that pressure, that peer group of parents pressured the government into centralizing biliary atresia and that was the consensus—it was parent to parent and all of this back in 1999 so all pre-widespread of internet, social media, pre-Facebook, pre all of that and still parents found each other and the word from parent to parent was, you know if you have a child who's born with biliary atresia don't agree to have surgery anywhere just go to these two centers go to King's College Hospital or go to Birmingham where we know these are high-volume centers, we know they've got the expertise, we know they've got published good outcomes, less complications than any of the other low-volume centers and it was all driven by parents and by by that pressure on the government being put by parents. Again, it became law that anyone born with biliary atresia would get their surgery done in these hospitals. But again, the slight difference from hypospadias is going to be how rare it is to have biliary atresia in the first place.

The only thing I could think of that the only condition that I could think of that is high in volume but also high in complications is hypospadias. Because generally really common conditions tend to be low complications. You know, take having an inguinal hernia, having a groin hernia, having an undescended testicle, they're quite common, but they're also quite low in complications. The only thing that is quite as common is to be both common and have high complications in hypospadias. So, it becomes a difficult process to try and say, well, we need to centralize care of hypospadias to a few centers that have had good outcomes and have continuous evaluation of their outcomes. It's not just a one-off where you say, well, we once looked at how hypospadias outcomes and that was good. No, you just need to continually assess the outcomes and ensure that that's up to standard. You're maintaining a low complication rate that would allow you to carry out the surgeries safely for families because it is not unusual to have a family go through hypospadias re-operation after re-operation with long-term consequences, you know, on both the boy or the man who's had the surgery and the parent.

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.