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Knowledge gaps and information seeking by parents about hypospadias

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Extended Summary

Introduction—Parents making complex decisions about hypospadias surgery may experience anxiety and uncertainty related to multiple sources of information with questionable reliability and limited relevance to their concerns.

Objective—The purpose of this study was to identify knowledge gaps, information-seeking behaviors, and informational needs of parents making decisions about hypospadias surgery as an initial step in the development of a hypospadias decision aid.

Study design—We conducted semi-structured interviews with English-speaking parents (18 years of age) of children with hypospadias, inquiring about gaps in their knowledge, information-seeking behaviors, and perceived informational needs (Extended Summary Table). We conducted interviews until no new themes were identified, analyzing them iteratively using open, axial, and selective coding. We used grounded theory methods to develop an explanation of the information-seeking process about hypospadias surgery.

Results—Of the 43 eligible parents, 16 mothers and 1 father (39.5%) of 16 patients participated: 7 preoperative and 9 postoperative with distal (8) and proximal (8) meatal locations. Parents were aged 21–43: 15 Caucasians and 2 African-Americans. Educational backgrounds and marital status varied across subjects. We identified five categories of knowledge gaps relating to hypospadias surgery: 1) epidemiology, 2) timing/technique, 3) perioperative experience, 4) long-term cosmetic outcome, and 5) long-term risk of complications. Information-seeking behaviors included searching the internet, discussing hypospadias with the child's pediatrician and/or

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Ethical approval

This study was approved by the Institutional Review Board.

Competing interests

The authors have no conflicts of interest to disclose.

urologist, and obtaining information from their social network. Most parents sought information online prior to and/or after consultation with the urologist, from parent blogs/forums, medical school/hospital websites, journal articles, and medical databases. Perceived informational needs included clear and reliable information online, images of mild degrees of hypospadias, and images of repaired hypospadias cases. According to the parents, video testimonials from other parents would help them relate to others in their social network and build confidence about the surgical process.

Discussion—The findings of this study contribute to our understanding of parental decision-making about hypospadias surgery by highlighting specific knowledge gaps and informational needs for inclusion in a decision aid. Study limitations include a small sample size that is typical and expected for qualitative research studies and the underrepresentation of fathers, minorities, and same-sex couples.

Conclusions—The Internet is the primary source of information most parents use to address knowledge gaps about hypospadias. Parents expressed concerns about the reliability and clarity of information and identified informational needs including parent testimonials and a wide variety of hypospadias images for inclusion in a decision aid.

Keywords

Decision-making; Pediatrics; Hypospadias; Qualitative research

Introduction

Parents making complex decisions about hypospadias surgery may experience anxiety and uncertainty related to multiple sources of information with questionable reliability and limited relevance to their **child's specific type of hypospadias** [1]. There are no prior studies about the process of parental information seeking about hypospadias and their specific informational needs related to the condition. Although there is a vast amount of information available online about hypospadias, several recent authors have expressed concerns about its quality and readability [2,3]. We hypothesized that parents may still have specific hypospadias-related knowledge gaps due to the high literacy level required to understand the online materials and the unreliable nature of the information sources.

In addition, several recent studies identified decisional conflict (DC) and decisional regret (DR) as significant problems for parents who elect hypospadias repair for their children [4-6]. The utilization of a shared decision-making (SDM) process may address the issue of DC and DR in hypospadias repair by engaging parents and physicians in decision-making. Decision aids facilitate shared decision-making by providing information about a condition, including risks/benefits/alternatives, and eliciting parental values and preferences. [7] The purpose of this study was to identify knowledge gaps, information-seeking behaviors, and informational needs of parents making decisions about hypospadias surgery for their sons as an initial step in the development of a hypospadias decision aid.

Materials and methods

Study participants

We identified parents (18 years old) whose sons had documentation of hypospadias when they visited a pediatric urology clinic for an appointment between October 2017 and January 2018. We contacted them after their visit via telephone to discuss study participation and obtained verbal informed consent. **It was not feasible to do in-person recruitment for this study due to several logistical factors including: a) the high volume, complex nature of our clinical practice, b) multiple, ongoing research studies with similar recruitment needs, and c) lack of available space in the clinic for recruitment/consent. Telephone recruitment is advantageous because it minimizes disruptions to the clinical workflow and affords access to patients seen at satellite clinics. At the time of recruitment, we gave parents the option of doing a recorded in-person interview, video chat, or phone call.** We included parents of postoperative patients (surgery <6 months prior) and those who were awaiting repair, excluding parents <18 years old and those who did not speak English. Each participant was compensated \$20 for study participation. Our Institutional Review Board approved the study.

Data collection

We developed a semi-structured qualitative interview script based on a review of the hypospadias literature and consultation with seven pediatric urologists at our institution. A qualitative researcher (JP) conducted all interviews by telephone **as per parental preference**. Qualitative interviews by telephone **may limit participants' emotional distress because of the comfort experienced through virtual communication** [8,9]. **They were also logistically easier for our families, many of whom live far from the academic medical center.** The Extended Summary Table includes a selection of the open-ended and directed questions we asked during the 30- to 60-min interviews. Interviews explored the parents' role as proxy-decision-makers, inquiring about their knowledge gaps, information-seeking behavior, and informational needs regarding the decision about hypospadias surgery. We audio recorded, professionally transcribed, and checked the interviews for accuracy. We conducted interviews until no new themes arose from additional participants, thereby reaching theoretical saturation. **The minimum number of participants required to reach thematic saturation in a grounded theory study is variable, although many qualitative researchers have suggested that 10–15 participants is usually sufficient [10]. Thematic saturation occurs when no new themes emerge from the coding process and therefore, only the researcher performing the data analysis can make this determination. In a grounded theory study, the researcher should set aside any preconceived notions about what topics "need" to be discussed or addressed. The topics of importance emerge from the data analysis based on the participants' responses. The focus in qualitative interviews is participant-centered and is similar to a patient-centered one, as compared with a physician-centered, clinical interview.**

Analysis

We used NVivo qualitative research software (QSR International, Doncaster, Victoria, Australia) to organize and facilitate data analysis of the interview transcripts iteratively

using grounded theory methodology. Grounded theory is a well-established qualitative research methodology that social, behavioral, and clinical scientists have used for over four decades. It works from the “bottom-up” using observations as they emerge from systematic analysis of data unlike “top-down” deductive approaches [11,12]. The participants’ “lived” experiences, devoid of the researcher’s preconceived ideas or notions **about which topics “need” to be addressed**, form the basis of qualitative data [12].

This approach is particularly useful where researchers have limited knowledge about the phenomenon of interest, as is true in this case regarding parental information seeking about hypospadias surgery. Analysis using grounded theory methods entails an iterative process of reviewing interview transcripts looking for patterns or themes.

We began by independently performing open coding of the interview transcripts, analyzing them line-by-line to develop provisional concepts [15]. Two of the authors (KC and JP) compared and collapsed the provisional concepts into categories [16]. During axial coding, we focused specifically on an emerging category and we used selective coding to identify the core concepts. We integrated the core concepts into a theoretical framework of the information-seeking process for hypospadias surgery [16]. In addition, we used theoretical sampling, which is the process of data collection directed by evolving theory, to choose participants, modify the interview guide, and add data sources as the study progressed [13-15].

Results

Sample

Of the 43 parents we attempted to contact via telephone, 22 were not reachable, 4 refused to participate because of a lack of interest and 2 parents were not eligible: 1 parent was a foster parent and the other parent stated that their son did not have hypospadias. Of the 21 eligible parents whom we contacted, 17 agreed to participate in the study (81%). There were 16 mothers and 1 father who participated: eight preoperative and nine postoperative, 15 Caucasians and 2 African-Americans, ages 21–43. Educational backgrounds and marital status varied across subjects (Table 1). We interviewed two parents (mother and father) of the same patient for 17 parent interviews regarding 16 patients. Urethral location was distal in 8 patients and proximal in 8 patients.

Knowledge gaps

Parents described feeling overwhelmed and lacking in knowledge and guidance at the time of diagnosis. We identified five categories of knowledge gaps relating to hypospadias: 1) epidemiology, 2) timing/technique of repair, 3) perioperative experience, 4) long-term cosmetic outcome, and 5) long-term risk of complications; Table 2 contains representative quotes for each. Specific knowledge gaps about epidemiology included the cause of hypospadias, prevalence of the condition, and the spectrum of disease severity. Parents had questions about the basic steps of hypospadias surgery and the indications for a one- vs two-stage repair. They also expressed uncertainty about the anticipated duration of the procedure, the efficacy, and adverse effects of caudal blocks used for postoperative pain

control, and the potential concerns of childcare providers regarding catheters and wound care. Finally, there were knowledge gaps about the definition of a “normal penis,” the expected postoperative appearance of the penis, and the amount of time a patient would be at risk for complications in the postoperative period.

Information-seeking behavior

Information sources included the internet, the child’s pediatrician and/or urologist, and the parents’ social network. Most parents sought information online before and/or after consultation with the urologist, from parent blogs/forums, medical school/hospital websites, journal articles, and medical databases. Interactions with providers helped to clarify information gathered online and helped build confidence and trust in the surgeon. Table 3 contains representative quotes regarding parental information-seeking behavior about hypospadias.

Informational needs

Parents suggested that high quality, clear, and reliable information about hypospadias would help them make decisions about surgery that were more informed and satisfactory to them. They also expressed a desire for images of mild degrees of hypospadias and repaired hypospadias cases. In addition, they thought that video testimonials from other parents would help them relate to others in their social network and build confidence about the surgical process. Table 4 contains representative quotes regarding parental informational needs about hypospadias.

Discussion

The findings of this study contribute to our understanding of parental information seeking about hypospadias surgery. Most parents sought information online to address specific knowledge gaps about the condition including epidemiology, surgical details, and long-term outcomes. Many expressed concerns about the reliability and clarity of their sources, although interactions with providers helped parents to clarify information, build confidence, and trust the surgeon. They also identified several hypospadias-related informational needs including parent testimonials and a wider variety of hypospadias images for inclusion in a decision aid. **We do not routinely distribute hypospadias handouts to our parents in the preoperative period. We hope that our hypospadias decision aid will fulfill our parents’ educational needs in the future.**

Several key findings from our study will contribute to the future development of a hypospadias decision aid. First, we noted a number of specific content areas that a hypospadias decision aid should address in an educational module. Second, the decision aid should be adaptable for use in the clinical setting with the provider as well as online (as a website for smart phone application) to allow for clarification of information throughout the decision-making process. Third, the decision aid should emphasize audiovisual content in various formats including photographs, medical illustrations, and parent testimonial videos in order to represent the wide spectrum of hypospadias severity and help parents build connections to others with a shared experience. **Although some parents mentioned their**

participation in online forums/blogs about hypospadias, they also raised concerns about the quality of information and biased viewpoints on these types of websites. They expressed a preference for high-quality, clear, and accurate information about hypospadias including testimonials from other parents.

One of the strengths of our study was the inclusion of parents with diverse demographic characteristics (i.e., marital status and educational background) whose sons experienced a wide spectrum of hypospadias severity. Although our sample included parents of various educational backgrounds, there was an overrepresentation of college-educated participants as compared to the state of Indiana [16]. We included parents of pre- and postoperative patients in order to capture all phases of the process. We thought that postoperatively, parents would have a unique perspective on their decision-making process, perioperative experiences, and decisional regret that could inform potential content areas for the decision aid.

The small sample size limits generalizability of our findings and is typical and expected for qualitative research studies. Another limitation is the underrepresentation of fathers, minorities, and same-sex couples. The small number of minority participants reflects the racial composition of our local area whereas the predominance of mothers in our sample may be because our electronic medical record typically lists mothers as the primary contact. Although we inquired about participation of all male partners, we were able to recruit only one. In future studies, we plan to apply purposive sampling techniques to focus on recruitment of fathers, same-sex and minority parents (**including Latinos**) on the day of surgery. Purposeful sampling is a technique widely used in qualitative research for the identification and selection of information-rich cases for the most effective use of limited resources [17].

Our findings are consistent with the limited literature on parental decision-making in hypospadias surgery [5,6,18]. Keays and colleagues identified “priority domains” for a patient-reported outcomes measure for hypospadias patients including satisfaction with urination, appearance, and erection, and overall well-being [18]. Although the parents in our study expressed similar long-term concerns, they also cited perioperative concerns and knowledge gaps about the epidemiology of hypospadias. The additional concerns we found are likely due to the timing of the interviews relative to surgery and the content of the interviewer’s questions.

In the next phase of our work, we will engage parents and researchers in the co-design of a decision aid to help parents make decisions about hypospadias surgery. Our recently published theoretical framework of the parental decision-making process, including information-seeking behaviors, will inform our guided discussion during a series of focus groups with parents, pediatricians, and pediatric urologists [1]. **We hope that our decision aid will fulfill our parents’ hypospadias-related educational needs in the future. In addition, we plan to implement a postoperative protocol for hypospadias patients in order to standardize clinical care and facilitate data collection for research purposes.**

Conclusions

The Internet is the primary source of information for most parents **we interviewed** wishing to address knowledge gaps about hypospadias. Parents **we interviewed** expressed concerns about the reliability and clarity of information and identified informational needs including parent testimonials and a wide variety of hypospadias images for inclusion in a decision aid. Our goal is to create a decision aid prototype that we can refine and pilot-test with parents of hypospadias patients. In future studies, **we plan to measure hypospadias knowledge, decision aid acceptability, and decision outcomes such as decisional regret.**

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Table 1

Demographics of parent participants and their sons at the time of the interview.

No. of parent participants	N = 17
Median age at interview (interquartile range)	31 (26–34)
Parenting role (%)	
Mother	16 (94.1%)
Father	1 (5.9%)
Relationship status (%)	
Single (never married)	3 (17.6%)
Married	10 (58.8%)
Divorced	4 (23.5%)
Race/ethnicity (%)	
Caucasian (non-Hispanic)	15 (88.2%)
African-American	2 (11.8%)
Education level (%)	
Some high school	1 (5.8%)
High school graduate	4 (23.5%)
Some college	1 (5.9%)
Associate's degree	2 (11.8%)
Bachelor degree	5 (29.4%)
Graduate degree	4 (23.5%)
Timing of interview relative to surgery (%)	
Preoperative	8 (47.1%)
Postoperative	9 (52.9%)
Meatal location ^a	
Glans	1 (5.9%)
Distal shaft/subcoronal	7 (41.2%)
Mid shaft	3 (17.6%)
Penoscrotal	5 (29.4%)

^a 17 parents of 16 patients: one mother/father dyad.

Table 2

Representative quotes for parental knowledge gaps about hypospadias.

Epidemiology	
"I don't think I had any questions to be honest. I was just more concerned on like, what it was, how can we fix it, what causes it?" And, that was all just given to us, like-So, after that it was just, okay. How soon can we fix it and what all is going to take place?" (PRE-16) ^a	
"I also had no idea what to expect or that until I did research, I didn't know there could be different degrees of the problem, and then I also didn't realize how severe our son's case was until the first meeting." (POST-4)	
"I also looked up a few, I think they were peer-review journals about, they provided some statistics about how often boys have this problem and the fact that they still don't know exactly what causes this. So, I couldn't find any solid information about what causes this." (PRE-6)	
Timing and technique of repair	
"[The diagnosis] was at birth. [Our son] was born super early and they tried to get a catheter in and they weren't able to locate his pee hole and they realized it was at the base of his penis and that he would have to get surgery to fix that at a later date. They didn't say, like, when we have to get it done. They just said it would probably be when he's more stable since he was born so early." (PRE-12)	
"I think it's more just when we get to talk to [Dr. X] again. I kind of [have questions about] how they go about doing it. Because I don't know, I can't remember what they told to my wife just because it's been a couple months since we had that appointment." (PRE-12)	
"I remember Dr. X used their fingers at a couple of points and drew some things and it is hard for me to remember at this point how they did it. I just remember something clicked and I understood better what they would be doing in that first surgery. The second surgery I understood where they were making the tube and that, but I think that first piece I was clueless about the curvature and kind of straightening that out." (POST-4)	
Perioperative experience	
"I felt pretty confident. The one thing that was a little confusing, I think, was I had read, again I think in one of the blogs, about how they had to double diaper their son with the catheter, and then in our preop class, I specifically asked about the double diapering because I was trying to get an idea of the care, to decide if he would be able to go back to daycare or not for that time period." (POST-4)	
"We were very concerned with the actual surgery. Like, how long does it take, does he have to be on crutches? This is one of my main worries, like at this age, he has to be on crutches for two hours and the doctor mentioned something that, for pain relief, they do something. Not exactly like an epidural but it is similar. And, so, we wanted to know more about that ... and how painful that will be and, another thing is like, is it guaranteed that this will be fixed." (PRE-6)	
Long-term cosmetic outcome	
"I think that is kind of what I touched on earlier about not having seen-like I was left to see pictures of-and I'm not sure that this is something that's easy to gain-of what it looks like in 10 years and I think that we're going to achieve a fairly normal-looking appearance but I just don't know." (PRE-8)	
"I honestly don't know [how his penis will look when he gets older]. I mean, I don't think it will be a "normal" penis but I don't know really what to expect. Mostly because I wasn't at the appointment. I'm not sure if the doctor went over that with [my partner] or not. But, I would, I mean, I would assume that it would be fairly close to what a normal penis looks like especially with him being so young and being able to recover pretty quick from that surgery." (PRE-12)	
"I tried to go and even just search the internet for pictures of what a repaired hypospadias looks like and there's not a lot out there. From my perspective, and I don't know that every parent would really like this, but just as someone who does have at least a little bit of a medical background, I'd like to know what it looks like when it's repaired as a child and then what it looks like, you know, as they get older." (PRE-8)	
Long-term risks of complications	
"Well that and you know what is the lifelong, I know that there are some risks of a fistula, if there is a leak or if it is too tight, so how long. Is that a lifelong risk? Is that something that will present itself later in the following years?" (PRE-2)	
"I think that we kind of went into it not knowing what to ask which is why we're now in the situation of having to have a second appointment. I think, so, my fiancé does not have a medical background but he has a research background. So, you know, he is big on statistics and, you know, what are the outcomes and what are the failure rates and all that fun stuff." (PRE-8)	

^aPRE = preoperative; POST = postoperative.

Table 3

Representative quotes for information-seeking behaviors about hypospadias.

Online searches	
<p>"I started kind of with Wikipedia to see what are the medical terms for these things. And, then I also looked up a few, I think they were peer-review journals about, they provided some statistics about how often boys have this problem and the fact that they still don't know exactly what causes this." (PRE-6)^a</p> <p>"So my question is the risk factor is a fistula. There could be a leak in the tube and he could have to have another surgery. That is the negative stuff I found on Google. I was like wait a minute is there a tube in his penis for his whole life? I am still a little confused on that." (PRE-2)</p> <p>"Parents commenting on the surgery [on blogs] either helps [or it doesn't]. It was too extreme. It was either great or horrible. I recognize that I don't know. I don't write on blogs. I kind of feel like typically people write their complaints more than [anything]." (PRE-2)</p> <p>"I looked on the internet for a few things. I found a blog for a parent that had a child with hypospadias that kind of documented their journey through the surgery and then kind of the after effects. I looked on the IU website at the articles that had been published by his physician, just to kind of get an idea of [Dr. X's] background and areas of expertise there. Then through research, I also found out about the, I think it was called the PANDA Study, about the effects of anesthesia on children, which was still ongoing at the time. I don't know if it is completed at this point, but I had just done some different research on that." (POST-4)</p> <p>"We just, it is just when you get on and you hit Google and then you just follow the links to the journals and this medical doctor's practice, and this guy's practice. And there were adults who had the surgery as a child who were giving like first hand, you know, this is what I remember, these are the issues I had. So, that was helpful too, to know that kids had been through it had put forth their experience." (POST-1)</p>	
Interactions with providers	
<p>"Talking to the doctor is really helpful to me because if there is something that I read that I didn't quite understand, you know, because they use all those big terms, they can put it in a little bit layman term, you know, and let me know, well, really, this is all it's saying. Reading stuff is better for me. So, like reading stuff, reading up on the internet before we ever saw a doctor, I already had a decent idea of what was going on and what I was dealing with and then the doctor filled in the blanks." (POST-10)</p> <p>"[Dr. X] kind of came in and looked and the things that [Dr. X] was explaining that what I saw on Google and I knew that it was true I started asking the questions that I found on the blog." (PRE-2)</p> <p>"I think reading information in simple language (because I don't have any medical background) is helpful. When a doctor explains to me, also being English as my second language, you know, English not everything immediately, especially like medical terms resonate with me. So, when I go back and read and find information that is in simple language and they have photos along with it, and I immediately am able to search extra so if I read about something and I have no idea which part of the body that thing is, then I can Google that word and learn more. So, I kind of learn on my own pace and then I like having a picture helps, so I can compare like how a normal one should like and how one that has had the hypospadias looks like and then I compare those, compare it with my child." (PRE-6)</p> <p>"To be honest, I'm trying to remember [the risks] specifically, but it's hard with the wording Dr. X used, you know, like doctor jargon. And, I think too, like given in October when I went and saw him again, and so February seemed far off. So, I feel like as we get closer that I might, you know, call them or they'll call me and I can talk more specifically. But, I just remember [the risks] not being high percentages, and so it didn't bug me that much." (PRE-12)</p> <p>"[Dr. X] was very thorough and [Dr. X] made sure that any questions we had, even after [Dr. X] initially met with us, when we went back and started researching things on our own, if I called, [Dr. X] would call me back. Not just a nurse, but [Dr. X] would call back and speak to me on my concerns. So [Dr. X] really made us feel like we understood, he understood, everybody knew that we were all on the same page." (POST-1)</p> <p>"I never looked it up to be quite honest. We mostly just took it at face value from the doctor. We didn't really do any research to find out what it is or what causes it because the doctor said it's just something that even if he had been born at a normal age, he probably still would have hypospadias. It's just a mutation that children get. So, we decided, all right. Like I said earlier, at that point in time when we heard about it's just like, okay, it's something that we can wait until another day to really worry about and learn more about." (PRE-12)</p>	
Social network	
<p>"We'd never seen it. You know, me, my mom had never seen it. Being a nurse. You know, I had never heard any of my friends or family members talk about somebody having someone that was, you know, born with that, you know, hypospadias. So, to me, it was so rare, no one's ever heard of it. I mean, everybody I told, no one went, "Oh, yeah, I've heard of that." So, in the doctor world, though, I guess they hear about it pretty often. He was just super reassuring." (POST-10)</p> <p>"I guess the numbers made me feel a little bit better that, you know, I hadn't heard of it, and my circle of people hadn't ever had to deal with any of it, but there are people in Indiana, in the United States that do this all the time and have to, you know, fix things like this all the time." (POST-10)</p> <p>"I did [talk to family members and friends to try to get information about hypospadias] and nobody had even heard of it. From the research that I've seen, it is rare to have it." (PRE-15)</p>	

^aPRE = preoperative; POST = postoperative.

Table 4

Representative quotes for informational needs about hypospadias.

High-quality, clear, and reliable information

"They told me not to [go on the Internet and Google 'hypospadias'], which I'm glad I didn't because, you know, you always get information and you kind of overanalyze these when I do that. So, I don't do the Google thing because if you look at Google, anything, like, you type in, it sends you to everything and you think you have that." (POST-13)^a

"I mean I was concerned about anesthesia and so at the same time, I say I am a "Google monster", I also learned that raised my anxiety". (PRE-2)

"I think I have a more discerning eye than maybe than the general public that's gonna [sic], you know, go to Wikipedia and kind of understand that. I don't remember the initial kind of websites that it took me, too. But, I think that the danger behind it is that people don't know how to use the internet appropriately and get accurate information." (PRE-8)

"I don't really like-and I know lots of people do-Dr. Google-but everybody's dying if you read the internet. Every condition leads to that. So, I try really hard to stay away from the internet in terms of searching through things because I think you always hear the worst case scenario." (POST-9)

"If you're getting ready for a surgery, I think in those terms, like when one person can't be there that wants to be, I think in that way, sometimes the video and stuff like a handout or something like that would give more information. Or, like a reliable place on the internet. Because the internet has everything. What sites can I trust to look at to be connected to families that have gone through this?" (POST-9)

Images of mild hypospadias

"I just went online on my phone and started looking it up and reading stuff and seeing images of what it could have been. Really, I didn't see any picture of what my son looked like comparatively. Which I was glad. Because some of the images that they show are just horrific. I was just like, 'Oh my gosh, this is how bad it could have been.' His was literally, you know, almost, you didn't even know it. The only reason I would have known is because they didn't have to circumcise him." (POST-10)

"When we knew the surgery was coming, we went online and researched everything we could about it, including videos or images of this is what it looks like if you don't have the surgery, this is what it does when you do, this is what it does after. So, I feel like we were prepared. The only trouble with that is once you get on there, they show the worst of the worst and you can fall down a rabbit hole. But at least we kind of had an idea going in what to expect." (POST-1)

"I think the most helpful part was the information telling me that it wasn't in the right spot and that it's corrective. Well, from the way the doctors were explaining it to me where the hole was, I couldn't find a picture anywhere. So, I mean, his was that high up. Everything [online] showed like how drastically bad it could be. But, he was such the low end of it, that made me feel so much worse when I see [sic] how the bad ones are." (PRE-15)

Images of repaired hypospadias

"I do [have some concerns about what my son's penis will look like as an adult] and ... I tried to go and even just search the internet for pictures of what a repaired hypospadias looks like and there's not a lot out there. From my perspective, and I don't know that every parent would really like this, but just as someone who does have at least a little bit of a medical background, I'd like to know what it looks like when it's repaired as a child and then what it looks like, you know, as they get older." (PRE-8)

"I haven't thought about it, how it looks like. You know, I know that we have to have some extra care. I actually have not imagined how it will like or even how the tube will like ... I didn't imagine how it's going to look like but now that I think about it, I assume there will be some Band-Aids around the head of the penis and that a tube will come down? 'I'm not 100% actually sure how it's gonna [sic] look like.'" (PRE-6)

"I think his biggest concern at the time was appearance. Is it going to look normal? Is it going to look right? Is it going to look like every other guy typically looks, you know?" (POST-10)

Testimonials from other parents

"I would say for sure getting other parents experiences would be helpful. I don't know if much of it would kind of matter what they considered, but maybe just hearing from parents who had children with hypospadias, because I hadn't heard of it until our son was born ... I had no idea what to expect or that until I did research, I didn't know there could be different degrees of the problem, and then I also didn't realize how severe our son's case was until the first meeting. So maybe just even hearing about different families going through the same thing and kind of what to expect would have been helpful." (POST-4)

"I also read some forum, not the patient portal, but you know, other [parent] forums you know, I don't know how credible they are but you know, sometimes like people share their own experiences, not like scientific but just to see that, you know, other people have been in the same boat at some point." (PRE-6)

"I think it probably would have been a little bit helpful [to watch video testimonials by other parents]. Ease some, easing anxiety or nervousness maybe, you know, knowing that other parents had gone through it and were okay with it. Like I said, I was okay with my doctor and the fact that he had a child have to go through it, too. And, I didn't talk to a bunch of other parents, but I would imagine if there was a board of people out there that had to deal with that, that would make me, I mean, I would say that about anything. You're dealing with something, it's always nicer to have other people who have gone through it. But, yeah, that probably would have been helpful to me." (POST-10)

"I think [watching video testimonials by other parents] probably would be helpful. I mean, ideally, to me, I would probably would rather sit with someone in a room and talk to them and hear what they have to say because you can see facial expression, you can see emotion in their face. Even in the video, you would be able to connect that way, you know, visually. Audio wouldn't necessarily be a total loss. You're still going to hear what people went through and obviously, be able to hear how it went for them but I think the video or in person would be better. But, if you said, 'This is the only thing I've got,' I would probably take it home and take it in and listen to it and feel like it was helpful." (POST-10)

"[Watching video testimonials by other parents] might be a little helpful. The only reason why I say that is because all through we make the best decision for ourselves, and maybe they made the best

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decision for them. And, so as far as everything else goes, what I see is, like, I'm in a lot of rooms, and I got some with a cleft palate, and in the hypospadias. So you like to see exactly what they went through. You try to listen to them and they just kind of, so in that aspect, I think that it is. That's why I said it would be a little helpful."⁷ (POST-13)

„I think [watching video testimonials by other parents] would definitely have been helpful. For us, it was already decided, but I still think any time, at that moment, I knew nobody and I just trusted in that case, I trusted the team of doctors working at the time that's what he needed. But, I think any time that you can relate to other people, that's going to make you have a little bit more confidence with what's going on, so I definitely think it would have been helpful."⁸ (POST-9)

⁷PRE = preoperative; POST = postoperative.

Extended Summary Table
Example questions from semi-structured interviews with parents of pediatric patients with hypospadias.

Knowledge gaps
Please describe your son's medical condition in your own words.
What were some of your initial questions/concerns about hypospadias?
What questions did you have for the urologist at the time of the clinic visit?
What concerns were not addressed at the visit?
Is there anything else that you would like to share
Information-seeking behavior
How did you get more information about your son's condition?
What information has been most (and least) helpful to you in understanding your son's condition?
What information has been most (and least) helpful to you in making a decision about surgery?
Is there anything I didn't ask about that you would like to share?
Informational needs
Think about how you learn or process medical information. How helpful would the following options be for learning more about hypospadias surgery? Please explain why:
<ul style="list-style-type: none">• Watching/listening to video/audio testimonials of parents reflecting on the things they considered when making a decision about surgery• Listening to an audio description of the surgery• Watching an animated video of the surgery• Looking at photographs or drawings of the surgery with a description of the steps• Reading paper brochures and/or taking notes on paper during the clinic visit• Looking at a three-dimensional model of a penis to help visualize the surgery• Completing an interactive learning module on the Internet or your smart phone