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User-centered development of a hypospadias decision aid prototype

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Extended Summary

Introduction—Many parents who choose hypospadias repair for their sons experience decisional conflict (DC) and decisional regret (DR). We previously found that parental decision-making about hypospadias surgery is a complex process characterized by cyclic information-seeking to alleviate anxiety and confusion.

Objective—The objective of this study was to engage parents of hypospadias patients and pediatric providers in the co-design of a decision aid (DA) prototype to facilitate shared decision-making about hypospadias surgery and address DC and DR.

Methods—From August 2018 to January 2019, we conducted three co-design workshops with parents of hypospadias patients, pediatric urology and general pediatric providers to discuss their recommendations for a DA prototype. Activities were audio recorded and professionally transcribed. Transcripts and worksheets were analyzed by six coders using qualitative analysis to identify key aspects of a hypospadias DA desired by stakeholders. We conducted a collaborative design and prototyping session to establish key features and requirements, created a content map visualizing this work, and then developed a DA prototype.

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Conflicts of Interest

None of the authors have any conflicts of interest to disclose.

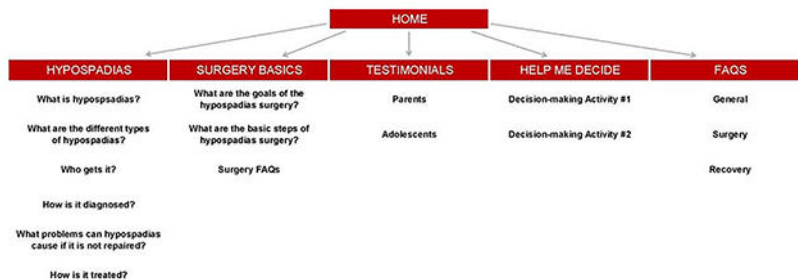
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Results—Parent participants included 6 mothers and 4 fathers: 8 Caucasian, 2 African-American; median age 31 years. Providers included pediatric urology (n=7) and general pediatric providers (n=10): median age 47.5 years, 83.3% Caucasian, 58.3% male, 58.3% MD's and 41.7% nurse practitioners. Participants created user-friendly, interactive DA prototypes with “24/7” availability that had three key functions: 1) provide accurate, customizable, educational content, 2) connect parents with each other, and 3) engage them in a decision-making activity. The prototype consisted of five modules (Extended Summary Figure). “Hypospadias Basics” includes epidemiology and a hypospadias severity scale. “Surgery Basics” includes goals, illustrated steps, and pros/cons of surgery. “Testimonials” includes videos of parents and adolescents discussing their experiences. “Help me Decide” includes a decisional conflict scale and a decision-making activity (i.e. values clarification method). “Frequently Asked Questions” covers general hypospadias information, perioperative expectations and a review of postoperative care.

Discussion—To our knowledge, this is the first DA prototype developed for a pediatric urology condition using a human-centered design approach to engage many key stakeholders in the development process. One limitation of this study is the small population sampled, which limits generalizability and means that our findings may not reflect the views of all parents or pediatric providers involved in hypospadias decision-making.

Conclusions—We created a parent-centered hypospadias DA prototype that provides decision support in an online, interactive format. Future directions include further testing with usability experts, providers and parents.

Graphical Abstract



Extended Summary Figure: site map of the Hypospadias Homepage consisting of five modules

Keywords

Decision making; pediatrics; hypospadias; qualitative research

Introduction

Parents considering hypospadias repair for their sons face an irreversible choice with potentially lifelong consequences. They must consider the trade-offs of possible cosmetic and functional improvement of the child's penis in light of the potential for postoperative complications. Recent studies have identified decisional conflict (DC) and decisional regret (DR) as a problem for a many parents who have elected surgical repair during childhood.[1–3] Shared decision-making (SDM) addresses the issues of DC and DR through joint

involvement of patients and health care providers in making health care decisions that are informed by the best available evidence regarding possible options and potential benefits and harms and that consider patient preferences and values.[4] The American Urological Association has endorsed this model of care in several recent guidelines on complex urologic topics.[5] Decision aids (DA) are tools designed to facilitate SDM by providing balanced information and helping patients construct, clarify and communicate what is important to them in making healthcare choices.[6–8] The goal of DAs is to promote high-quality decisions that are informed and consistent with the patient’s values and preferences. [9]

The current study is part of a multi-year project whose goal is to improve the care of hypospadias patients by developing an evidence-based DA to promote SDM in hypospadias care. In our previous qualitative work, we conducted a needs assessment of parents considering hypospadias surgery for their sons in order to investigate their decision-making process, knowledge gaps and information-seeking behavior.[10, 11] We found that parental decision-making about hypospadias surgery is a complex and multi-faceted process characterized by an initial period of information-seeking about the condition in order to alleviate anxiety and confusion.[11] Parents noted that online information about hypospadias has questionable reliability and limited relevance to their contexts and concerns.[11] Their informational needs remained salient from the time of diagnosis through the postoperative period, encompassing the initial diagnosis, clinic visit, day of surgery and beyond. In addition to demonstrating that parents wanted clear, reliable information on hypospadias, we also identified a number of specific knowledge gaps including the causes of hypospadias, the spectrum of severity, penile anatomy, and the definition of chordee.[10] Using this preliminary data as a guide, the objective of this study was to engage parents of boys with hypospadias, pediatric urology and general pediatric providers in the co-design of a DA prototype to help parents make informed, values-based decisions about hypospadias surgery.

Material and Methods

Theoretical framework and quality criteria

We used the Ottawa Decision Support Framework (ODSF) to inform the design of a hypospadias decision aid (DA) prototype, synthesizing data from parents and providers and the hypospadias literature.[12] [13] According to this framework, unresolved decisional needs (e.g. DC) adversely affect decision outcomes (e.g. decision quality). Decision support can improve decision outcomes by addressing decisional needs using clinical counseling, decision tools and/or decision coaching. In addition, we followed a set of quality criteria published by the International Patient Decision Aid Standards (IPDAS) collaboration.[12] Finally, we incorporated more recent evidence from the IPDAS regarding design of values clarification methods, strategies for risk communication and inclusion of patient narratives in DAs.[14–16]

Study participants

Parents—We identified English-speaking parents/caregivers (18 years old) whose sons (ages 1 week to 5 years) were diagnosed with hypospadias at a pediatric urology clinic

appointment between October 2017 and August 2018. Parents of postoperative patients (surgery <6 months prior) and those awaiting repair were eligible for inclusion in the study in order to engage them at various times during which they might use a DA. We excluded parents <18 years old and those who were not fluent in English given that language translation would not be feasible during a group discussion. We contacted eligible parents via telephone to discuss study participation and, if interested in participating, obtained verbal informed consent to participate in a co-design workshop to design a hypospadias DA prototype.

Providers—We used convenience samples of pediatric urology and general pediatric providers due to their availability and ease of access. We recruited pediatric urology providers, including attending physicians, fellows and nurse practitioners, from our academic medical center via e-mail. We excluded residents and medical and nursing students because of their presumed limited experience with hypospadias decision-making in clinical practice. We recruited general pediatric providers from a list of 49 registrants for a statewide pediatric continuing medical education (CME) conference for primary care providers at our academic medical center in January 2019. We contacted providers via email on two separate occasions, one week apart, to discuss study participation and obtained informed consent. We included general pediatric providers in the study because they are typically the first point of contact for parents after the diagnosis of hypospadias in the newborn period and may influence parental decision-making about hypospadias. The study was reviewed and approved by our Institutional Review Board (protocol # 1511846401).

Data collection

We conducted three separate “co-design workshops” from August 2018 to January 2019 at our academic medical center with parents of sons with hypospadias, pediatric urology providers, and general pediatric providers respectively to discuss their recommendations for a DA prototype. A co-design workshop is an in-person group session consisting of a series of guided activities during which a facilitator leads participants through the design process in order to create prototypes of a product or service. Provider workshops were incorporated into existing academic/CME activities to maximize the number of participants and minimize their absence from patient care. Each workshop lasted approximately 90 minutes. All activities were audio recorded and professionally transcribed, and participants’ responses were de-identified except for gender. We recorded participant gender in order to understand whether any of the comments captured the unique perspective of fathers versus mothers. Transcripts were reviewed for accuracy and reconciled prior to data analysis. Two members of the research team took extensive field notes during the sessions. Participants were compensated for their time.

The facilitation team consisted of two human-centered design researchers (one male, one female). They have a Master of Fine Arts Degree in Human-centered Design Research and a Bachelor of Fine Arts Degree in Visual Communication Design, respectively, and have extensive experience planning research activities, facilitating group discussions and collaborative activities and analyzing data.[17] In order to reduce the facilitating researcher’s bias from influencing the workshops and subsequent data analysis they engaged in “critical

self-reflection and transparency” about their preconceptions regarding decision-making about surgery, relationship dynamics with participants and analytic focus.[18] For example, they asked participants open-ended questions during the co-design workshops in order to limit the influence of their own values and opinions on data collection. They also involved peers in design and analysis of the co-design workshops and prototyping session.

Our approach was qualitative in nature and informed by human-centered design methodologies. Human-centered design is a form of qualitative research that includes elements from product development and participatory design, using abductive reasoning to start with a set of observations and find the simplest and most likely explanation for these observations.[19] Key practice components of human-centered design are building empathy, thinking by doing, making things visual, combining divergent and convergent approaches, and fostering collaboration and empowerment amongst stakeholders.[20] Human-centered design is appropriate to this work because it collaboratively explores an area about which little is known and uses guided group discussion and prototype development as part of its methodology in the design of stakeholder-centered tools.[21]

Each workshop consisted of worksheets and group discussions led by the workshop facilitators. A multi-disciplinary team with expertise in communication design, pediatric urology, and health services research developed the workshop guide based on previously identified themes from our interviews with parents. We asked teams of 3–4 participants to create a “device...anything real or imaginary,” to help parents of boys with hypospadias make decisions about surgery for their sons. We asked them to complete a “device co-design worksheet” consisting of a series of guided prompts regarding possible locations where they would use the device, format, function and any additional features of the device. They completed “device prototype” worksheets in their small groups focusing on format, function and content (Figure 1). The facilitator concluded the workshop with a group discussion to clarify their respective suggestions for the prototype.

Data analysis—First, our multi-disciplinary team of six coders analyzed the data from each of the three co-design workshops using qualitative content analysis informed by human-centered design methodologies to establish key features and requirements of the DA. We separated pieces of data from the paper transcripts and the participants’ worksheets onto individual slips of paper to facilitate data grouping and sorting. Our team collaboratively grouped all of the pieces of data by similarity, identifying key themes and labeling them to describe their content. We resolved disagreements by group discussion. Finally, we collaboratively organized these key themes by how they related to each other, creating a final affinity diagram; a visual representation of data groupings and relatedness.[22] Team members compared the affinity diagrams from all three workshops, identifying key aspects of a hypospadias DA desired by the included stakeholders. Data saturation was confirmed by examining the themes to determine that no new themes emerged. Next, we conducted a collaborative design and prototyping session with multi-disciplinary team members, including web developers, where we established key DA features and requirements and created a content map visualizing this work followed by a DA prototype.

Results

Demographics

The first co-design workshop included 10 parents (6 mothers, 4 fathers) of hypospadias patients: median age 31 years; 8 Caucasian, 2 African-American. Six were married, 2 were single, 1 was separated and 1 did not disclose his/her marital status. Two had a graduate or professional degree, four had a Bachelor's degree, two had some college, one was a high school graduate and one did not disclose his/her educational level. The second and third co-design workshops included pediatric urology (n=7) and general pediatric providers (n=10), respectively: median age 47.5 years, 83.3% Caucasian, 58.3% male, 58.3% physicians and 41.7% nurse practitioners.

DA co-design workshop

Participants in the three groups created user-friendly, interactive DA prototypes with “24/7” availability that had three key functions in common: 1) provide accurate, customizable, educational content about hypospadias, 2) connect parents to each other, and 3) engage them in a decision-making activity (Figure 1). They suggested that the DA might be used at home, work, daycare or the doctor's office. Key educational content included a multimedia overview of hypospadias and goals of hypospadias surgery with illustrations, photos, videos, and statistics to suit a variety of learning styles. They also recommended an illustrated severity scale with customizable information based on the degree of hypospadias severity, a summary of the pros/cons of surgery and a review of postoperative care/recovery to share with family members and childcare providers. Finally, they suggested parent testimonials about surgical decision-making and the day-of-surgery experience. Both provider groups recommended the inclusion of pre- and postoperative images and 3-dimensional models. General pediatric providers suggested implementing the DA in the newborn nursery and incorporating it into telemedicine consults and provider training. Pediatric urology providers recommended including a chordee measurement tool. Table 1 contains representative quotes from the participants regarding the function and content of the DA.

Design and Prototyping session

The study team engaged in a collaborative session to synthesize data from the three workshops and establish key features and requirements of our DA prototype (Figure 2). Because the included stakeholders wanted the DA to be available “24/7”, parents wanted the tool to be sharable with other caregivers, included stakeholders desired multi-media components, and because the majority of stakeholder teams created prototype apps or websites, we chose to create a web-based DA. We created a site map consisting of five modules (Extended Summary Figure). Based on the site map, we created a web-based DA prototype called the *Hypospadias Homepage* (Figure 3). “Hypospadias Basics” includes the epidemiology of hypospadias in the United States and a hypospadias severity scale. “Surgery Basics” includes goals, illustrated steps, and pros/cons of surgery. “Frequently Asked Questions” covers general hypospadias information, perioperative expectations, and a review of postoperative care. We included photographs and illustrations in the prototype to evaluate parental preferences for visual representations of hypospadias during subsequent phases of

prototype testing. "Help me Decide" consists of a decisional conflict scale and a values clarification exercise. "Testimonials" includes video narratives by parents.

DA Module Development

It is recommended that DA's include a "values clarification method" (VCM) to help patients consider how they value key aspects of a healthcare decision.[23] Their purpose is to "help patients clarify and communicate the personal value of options, in order to improve the match between what is personally most desirable and which option is actually selected." [7] [15] The most common types of VCMs are considering the pros versus cons, utility assessment with or without decision analysis, prioritization and rating scales.[15] We developed a VCM for the *Hypospadias Homepage* to facilitate the identification of: a) options (i.e. surgery or no surgery), and b) attributes of the options which affect the parent's preference (e.g. effectiveness of the surgery, recovery period, risk of complications, risk of long-term issues if not repaired). Multiple decision processing theories and the perioperative concerns identified by parents in our previous qualitative work informed the design of our VCM.[24–27] [10, 11] It consists of an abbreviated version of the decisional conflict scale (SURE) and a series of open-ended questions asking parents to identify options and consider various decision attributes and personal values relevant to the decision (Appendix A).[28]

Based on the recommendations of all stakeholder groups, we also developed a module of parent narratives (i.e. video testimonials) to depict a variety of experiences, both positive and negative, with decision-making about surgery and the day of surgery. [29] In order to minimize bias, we did not include any narratives about surgical outcomes to avoid influencing parental perceptions about complication rates.[29] We identified and recruited parents using the methodology described above in the Materials and Methods section. None of them had participated in earlier phases of the study. Videos were filmed by a professional video production company at our academic medical center or at the parent's residence/ workplace and were edited for content and brevity.

Discussion

In this study, we engaged many of the key stakeholders in hypospadias care in the co-design of a user-friendly, interactive hypospadias DA prototype with "24/7" availability. The key functions were to: 1) provide accurate, customizable, educational content, 2) engage parents in a decision-making activity and 3) connect them to each other through parent testimonials, blogs and/or chat rooms. Although parents desired direct communication with one another, we decided against this given the need for constant site monitoring and potential medico-legal concerns. We compromised by including parent testimonials to help parents feel connected to each other. Parents and providers had divergent recommendations regarding visual design of the DA prototype. Parents suggested basic illustrations/photographs of hypospadias whereas providers recommended more sophisticated three-dimensional models and chordee measurement tools.

Most DA developers regard the involvement of relevant stakeholders early on in the process as a crucial initial step.[30] Many have utilized focus groups as part of a "participatory design approach" to integrate patient/provider recommendations for design and content into

the development of DAs.[31–33] In addition to exploring key stakeholders' recommendations for a hypospadias DA, we included them as co-designers of DA prototypes in order to maximize the parent-centeredness of the DA. Workshop participants leveraged their expertise, incorporating their unique experiences into their design prototypes with the help of supportive design tools and guidance from design experts.[34] This hands-on, creative approach to DA prototype development encourages the expression of ideas that are difficult to put into words.[35] To our knowledge, no prior studies have engaged key stakeholders as co-designers of a DA prototype in this manner.

To our knowledge, this is the first DA prototype developed for a pediatric urology condition using a qualitative, human-centered design approach to engage key stakeholders in the development process. Another strength of our study is we used a common theoretical framework (i.e. the ODSF) and we adhered to the quality criteria for DAs outlined by the IPDAS.[12, 13] In addition, we incorporated more recent evidence regarding several key elements of DAs such as the design of values clarification methods and patient testimonials. [14–16]

One limitation of this study is that the small population sampled limits generalizability, thus our findings may not reflect the views of all parents of hypospadias patients or pediatric providers involved in hypospadias decision-making. It is possible that parents who chose to participate in the focus group or video testimonials contributed their own biases to the discussion. In addition, all of the pediatric urologists were from a single academic medical center which may reflect the biases of our group practice, e.g. likelihood of recommending surgical intervention and how bothersome complications are to us. Ideally, we also would have included older hypospadias patients, both repaired and unrepaired, as stakeholders in the development of the DA. Unfortunately, we encountered challenges in recruitment of this patient population due to their limited long-term follow-up in our practice. We plan to use social media to recruit them for a future phase of this study.

Despite the low sample size, our stakeholder group for this study included several fathers and racial minority participants unlike our prior study on hypospadias decision-making, which was more homogenous.[11] Another limitation is that some parents may have felt uncomfortable discussing sensitive issues in a group setting. Nevertheless, the study provides a rich description of a group of parents' and providers' recommendations for a hypospadias DA prototype. Another limitation of this study is the potential loss of data during analysis of workshop transcripts such as intonations of voice, body language and seating arrangements that can add meaning to the textual data.[36] This seems less likely, however, since most of the coders participated in the co-design workshops or took notes during the sessions.

Conclusions

Parents and providers desire a hypospadias DA that is user-friendly, interactive, customizable to their needs/concerns and available “24/7.” In future studies, we will conduct further testing of the DA prototype with usability experts, providers, and parents prior to launching a pilot test in the clinical setting.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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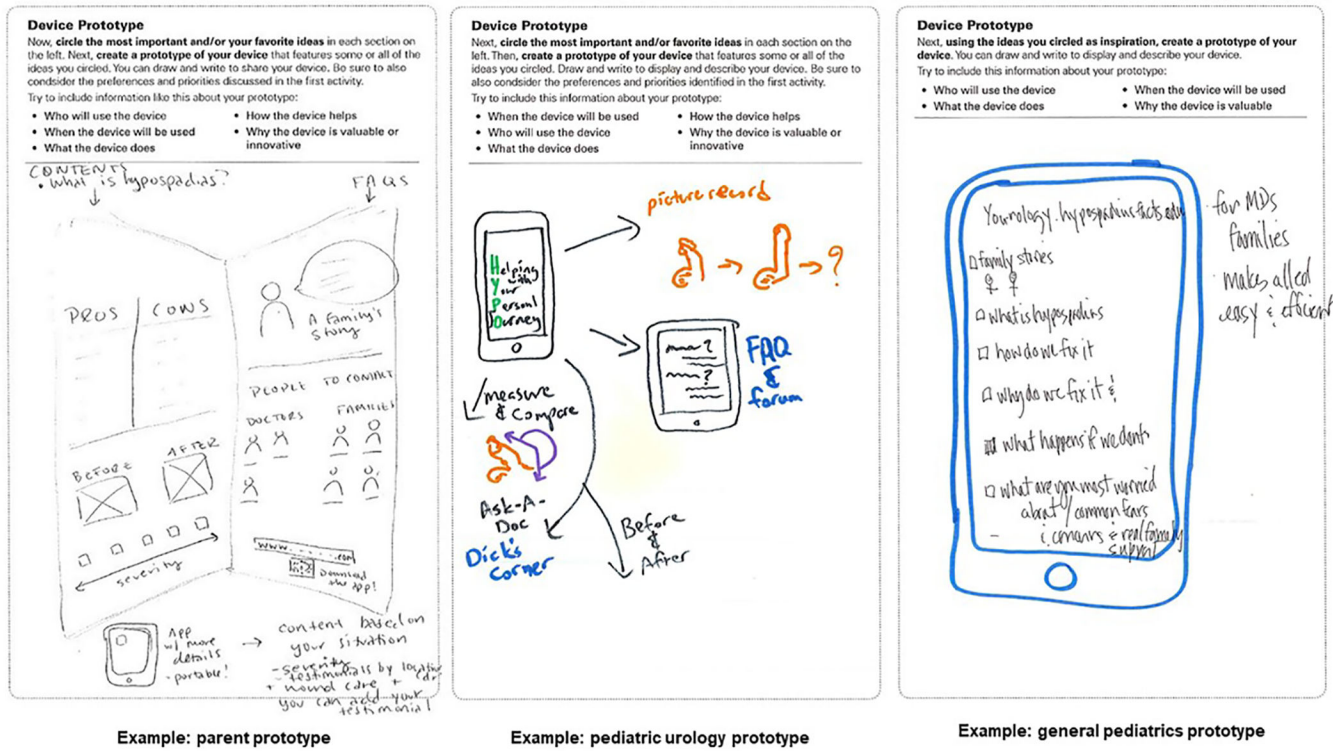


Figure 1: examples of hypospadias decision aid prototypes created by parents, pediatric urology and general pediatric providers respectively during three co-design workshops

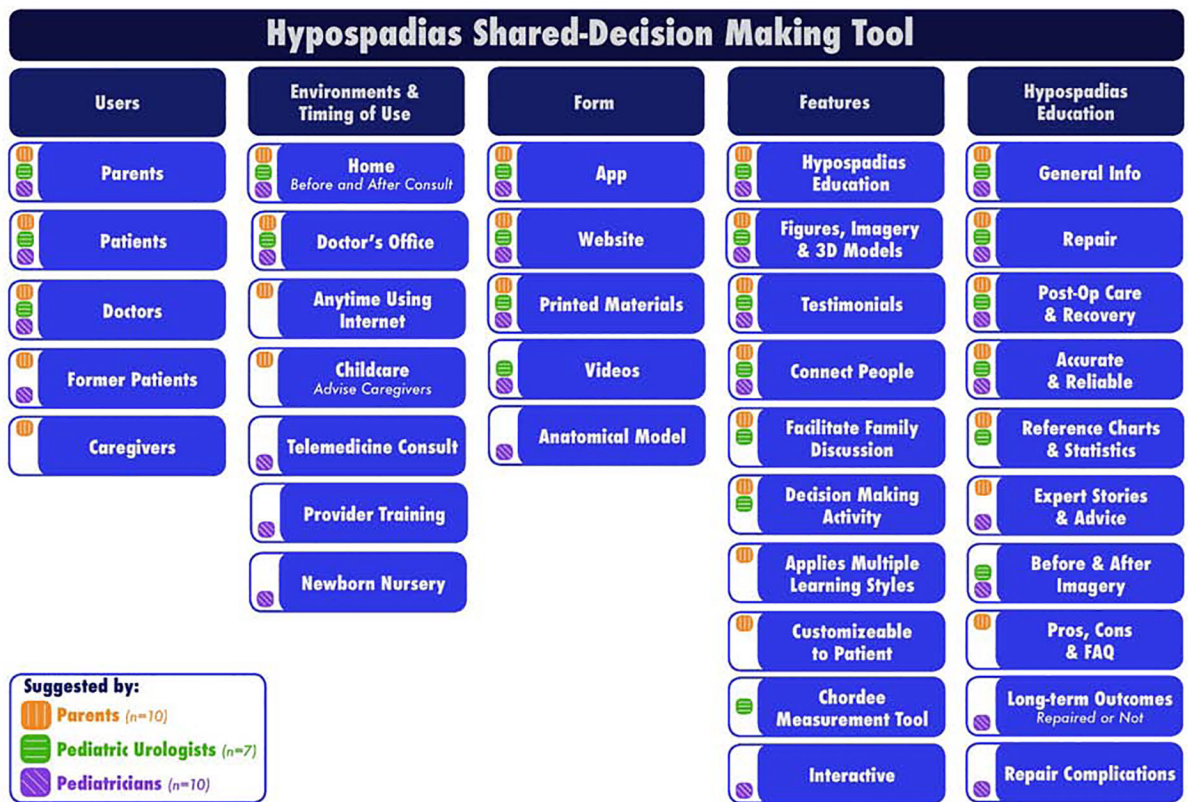
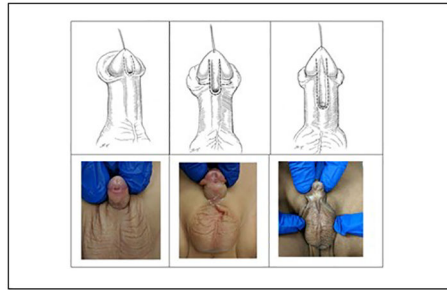
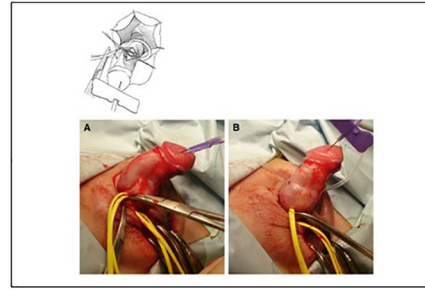


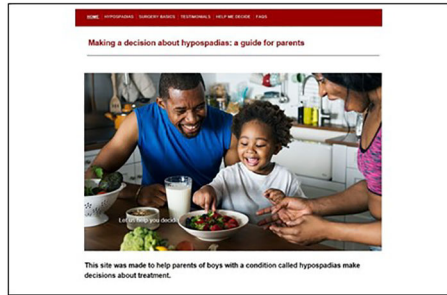
Figure 2. Summary of the key features and requirements of the hypospadias decision aid recommended by parents and providers



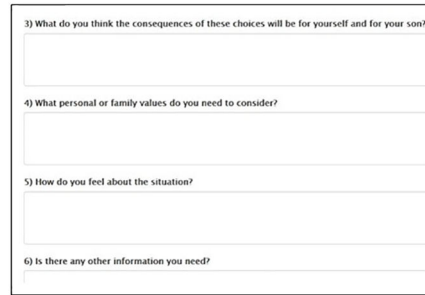
Severity scale demonstrate the spectrum of hypospadias



Photos/illustrations demonstrate the surgery step-by-step



Homepage contains a site menu, photos and quotes from parents



Values clarification exercise reviews decision attributes

Figure 3.
Selection of modules from the Hypospadias Homepage

Table 1:

Representative quotes from parent and provider workshops regarding “device” (i.e. decision aid) recommendations

	Parents	Providers
Function		
Connect people	“Specialists can blog on it but then also the parents could. ‘At this stage, we had this issue and because of that, we did this.’ The biggest one would be the sort of the process for recovery.”	“We thought of connections to families that would be willing to answer any questions on the outside. We talked about not only the step-by-step procedure but post-op care and what the families would be expected to do at home.” (F-PEDS)
		“It will help parents make the decision... whether or not they want hypospadias surgery. We will have a group discussion feature, reference chart, chordee measurement tool, ask child what they want and FAQ question submission. ” (F-GU)
Education	“Ours was an app to be used by the specialist and the parent at diagnosis. We all were in the same [boat] where we have no idea what the heck [hypospadias] was. I’d never even heard of it. The doctor would say, ‘ they’ll tell you about it, and you can go over this app thing. ’”	“We felt that the device would give information about the procedure and what’s going on. For the most part, it’s going to decrease anxiety of the family because they’re going to know the facts of what needs to take place.” (F-PEDS)
		“It could provide all the basic information to get them up to speed , I guess. That’s what your device is going to do. Provides them with more comfort about the experience.” (M-GU)
Visual models	The biggest thing... I liked about it was that you’d have some type of a 3-D model but it’s tailored because everybody is different. So, you could kind of tailor your own severity... it would show you a 3-D model and you can [show] typically what the end result is going to be and what it could look like down the road.”	“We really liked most the idea of an interactive app that would allow the families to kind of manipulate what was going on, what was the outcome. Another thing would be an interactive physical model as a prototype or a third option would be an augmented reality simulation.” (M-PEDS)
		“I would make something that’s embryologic: this is how the penis develops, this is how the penis develops when there’s hypospadias and then go through the different forms. It would be a three-dimensional model. ” (M-GU)
Content		
Surgery info	“It would have been nice to have an understanding beforehand about all the degrees... because I didn’t fully understand that there could be two surgeries and two stages. That was kind of confusing...”	“We could use any of the devices to demonstrate before and after procedure... demonstrate how the procedure is performed. ... inform the patients about what condition we’re diagnosing as having.” (F-PEDS)
		“I think the stages of pre- and post-op , how things progressed, too, would be good to include. Because initially, it’s like, “Wow, what just happened to that penis.” And, then, after six months you can hardly even tell.” (F-GU)
Multimedia	“Everything had to be interactive and everything had to have various learning styles. So, video, images, information, everybody learns differently. Again, 24/7.”	“We also thought that you needed an app for the patient that they could go home with. They would have a 3-D cartoon interpretation of the procedure... and, of course, research studies and testimonials. ” (F-PEDS)
		“You could sort out the, internet-based questionnaire that they do right after seeing this 3-dimensional video ..virtual reality.” (M-GU)
Testimonials	“...then have some testimonials from people that have had the surgery, their family experiences, contact information for doctors in your area that perform the surgery and then family testimonials from your area as well.”	“We did talk about testimonials from other parents. We thought it was very important that we gave testimonials for both: families that decided to go for the surgery and those that decided to wait...and maybe even teenagers who later decided to have the surgery so, that they could truly get the perspective.” (F-PEDS)
		“There should be a part for kids who have already had it done, like older kids, who can weigh in on their opinion. ” (F-GU)

F = female

M = male

GU = pediatric urology provider

PEDS = general pediatric provider

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