



Ask the parents: Testing the acceptability and usability of a hypospadias decision aid

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Keywords

Decision making; Pediatrics; Hypospadias; Qualitative research

Received 16 July 2021

Revised 16 December 2021

Accepted 10 January 2022

Available online xxx

Summary

Introduction

In previous work, we engaged key stakeholders to create a web-based decision aid (DA) prototype to facilitate shared decision making about hypospadias.

Objective

The study's objective was to use a human-centered design approach to assess the DA's acceptability and usability and revise it prior to pilot testing.

Methods

We recruited English-speaking parents (≥ 18 years old) of sons with hypospadias (≤ 5 years) for a two-phase process of semi-structured phone/video interviews to obtain feedback about our DA prototype. DA webpages included: "Hypospadias," "Surgery Basics," "No Surgery," "Family Stories," "Help Me Decide," and "FAQs." In both phases, participants viewed the DA using the "think aloud" technique and completed several validated scales to evaluate its acceptability and usability. In phase 1, we collected feedback about the "Homepage" organization, values clarification methods (VCM), and webpage content. In phase 2, participants searched the DA for answers to hypospadias-related questions, provided feedback on testimonial videos and VCM, and shared their preferences about data visualizations. All interviews were audio recorded. After each phase, transcripts were qualitatively analyzed to identify key areas for revision. Revisions were made between phase 1 and 2 to improve the DA's acceptability and usability.

Results

We interviewed 20 participants (10/phase): median age 33.7 years, 60% female, 80% White. Mean score on the Preparation for Decision Making Scale: 86.8 (out of 100). We revised: 1) VCM, focusing on pros/cons of surgery and question prompts, 2) "Homepage," adding webpage descriptions (Extended Summary Figure), 3) menu organization, 4) "Surgery Day" webpage, adding general anesthesia risk information, and 5) "Hypospadias" webpage, adding an icon bar graph to help participants visualize statistics. Participants thought the testimonial videos were relatable and the VCMs would prepare them for their visit with their child's urologist.

Discussion

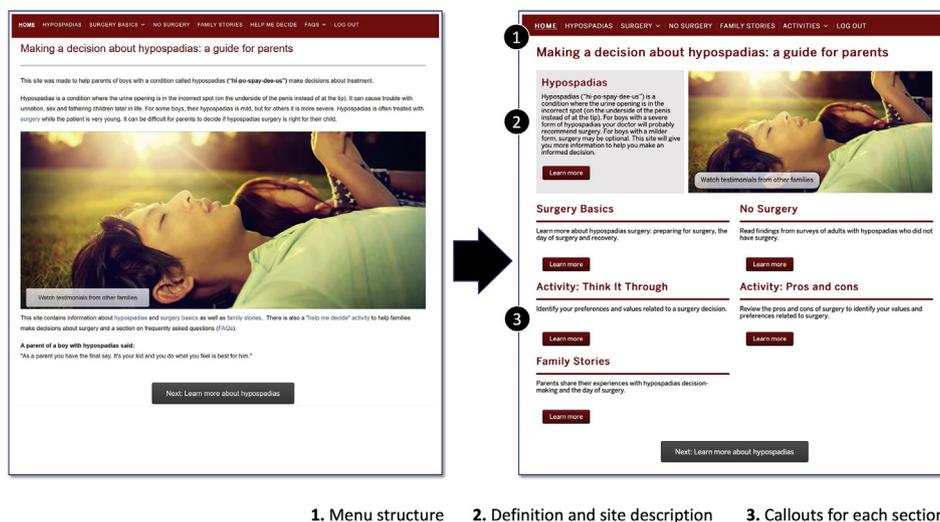
Ours is the first parent-centered DA developed and pre-tested for hypospadias. Using validated usability and acceptability scales, participants highly rated the DA in helping them arrive at a decision about surgery. Study limitations include the sample's lack of diversity (i.e., educated, health literate) and participants already decided about their son's hypospadias management before enrolling. To learn more about the DA's usability and acceptability, we plan to pilot test it in a clinical setting.

Conclusions

Participants found our DA informative in understanding hypospadias. There was a high perceived level of preparation for hypospadias decision making. Participatory research methods, such as "think aloud," may be helpful when testing DAs as they privilege the patient's experience.

<https://doi.org/10.1016/j.jpuro.2022.01.004>

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1. Menu structure 2. Definition and site description 3. Callouts for each section

Summary Figure "Homepage" revisions based on participant feedback. *Note.* The illustration on the left is the "Homepage," which was tested in phase 1. Using the feedback from phase 1, we reorganized the homepage, included webpage descriptions, and defined hypospadias more distinctively.

Introduction

Decision-making about hypospadias surgery is a complex and multi-faceted process, which may create anxiety and confusion for parents of hypospadias patients [1]. To address decisional conflict and regret among parents, we developed a decision aid (DA) to facilitate shared decision making (SDM) about hypospadias. SDM requires "the intentional and cooperative involvement of both patients and clinicians in the process of deliberation about care" [2]. The DA's purpose is to present up-to-date information; help the patient identify his or her values; and, provide guidance on how to communicate his or her values and concerns with others (e.g., partner, provider) [3].

As this study is part of a multi-year project, we have previously identified parents' knowledge gaps and information seeking behaviors related to hypospadias surgery; conducted a needs assessment of parents considering hypospadias surgery; and, explored providers' perspectives about SDM anchored on hypospadias [1,4,5]. Providers and parents collaborated in three co-design workshops to build the DA [6]. Based on the feedback, the DA was created as a website and included the epidemiology of hypospadias; steps of hypospadias surgery and its goals; pros/cons of surgery; testimonials from parents whose sons were diagnosed with hypospadias; exercises for parents to reflect on the impact their personal values have on their decisions; and, frequently asked questions about hypospadias, perioperative expectations, and postoperative care [6]. Each webpage included multimedia components (e.g., videos, illustrations, graphs).

This study's objective was to test the DA's acceptability and usability in two phases. This iterative process allowed us to identify issues with the DA, assess their severity, and propose changes prior to pilot-testing in the clinical setting. The goal was for users to consider their values, accomplish information-seeking tasks, understand the presented information, and recognize the DA's significance in their decision making about hypospadias surgery.

Materials and methods

Participants

We identified English-speaking parents (≥ 18 years old) whose sons (≤ 5 years) were diagnosed with hypospadias at a pediatric urology clinic appointment in the prior six months. Participants must have already decided about repair surgery for their son at the time of enrollment. The exclusion criteria were participants < 18 years old and those who were not fluent in English. A purposive sampling strategy was used to maximize diversity of the participants [7]. Most participants viewed the DA from a tablet/computer. We contacted eligible participants via telephone to discuss study participation and obtained verbal consent. Each testing phase included 10 participants, for a total of 20 unique individuals. The study was reviewed and approved by our Institutional Review Board (protocol #1511846401).

Decision aid website

The university's child health informatics research and development lab, which is composed of physician scientists and software engineers, developed the DA for an US-based audience. The DA included seven webpages: "Homepage," "Hypospadias," "Surgery Basics," "No Surgery," "Family Stories," "Help Me Decide," and "FAQs." [7].

Data collection and analysis

A mixed-methods approach was used for both phases, which occurred from November 2019 to November 2020 [8]. A research assistant (RA) with a health communication background conducted virtual semi-structured interviews. Prior to the interview, the RA helped the participant download Zoom, a teleconferencing software, on his or her device to enable screen sharing capabilities. The

participant received the DA website address once the interview began.

During the interview, the participant was asked a series of questions (e.g., Why did you choose to watch those videos?) about specific webpages. We used the "think aloud" technique, asking each participant to verbalize his or her thoughts in real-time as he or she viewed the DA [9]. At the conclusion of the interview, we administered several validated tools. Data were collected in two phases to ensure the suggested revisions from phase 1 improved the DA's usability and acceptability in phase 2.

All interviews were audio/video recorded and professionally transcribed. After each phase, three researchers on the team analyzed the transcripts using a qualitative thematic analysis to identify key areas for revision. Each researcher coded individually, then the group discussed their findings, identified themes, and resolved disagreements by consensus. The group developed strategies to alleviate the usability errors that were identified as problematic.

Phase 1 testing

The purpose of phase 1 was to collect participants' initial impressions. Due to time constraints, participants did not review the entire DA. However, at least half of the participants provided feedback on every webpage. Phase 1 focused on the "Homepage" organization and language and three webpages: "Hypospadias Basics," "No Surgery," and "Help Me Decide." The "Help Me Decide" webpage included value clarification methods (VCM), which are strategies to engage patients in evaluating "the desirability of options or attributes of options within a specific decision context, in order to identify which option he/she prefers" [10]. The VCM was designed as interactive quizzes to engage each participant actively in the process of deliberating about his or her values, preferences and priorities related to hypospadias. Demographic information was collected and two validated tools were administered: System Usability Scale (SUS) (measures a website's usability) and Decision Aid Acceptability Scale (DAAS) (measures a website's balance, length, amount of information, and clarity) [11,12].

Phase 2 testing

In phase 2, we attempted to simulate a real-life scenario in which participants were asked to recall the time when they faced the decision about hypospadias surgery. Using our DA, participants engaged in a self-guided experience. First, they participated in a scavenger hunt, which tested the DA's organization and clarity. For each scavenger hunt question, participants started on the "Homepage" and had to find the answer on the website. Afterwards, participants selected two of five testimonial videos on the "Family Stories" webpage to watch. Then, participants viewed two data visualizations, an icon array and an icon bar graph, which were located on the "Hypospadias Basics" webpage (Fig. 1). Data visualizations were used to enhance risk perception [13,14]. Both visuals compared how common hypospadias and cleft palate are; however, the denominator for the icon array was 250 and icon bar graph was 10 people, which resulted in a

whole number and fraction, respectively. Participants were asked what visual they preferred and why.

Next, participants viewed and answered questions about the updated VCM webpages, "Think It Through" and "Pros & Cons," located under "Activities" tab. Demographic information was collected and we administered 3 validated tools: the Preparation for Decision Making (PrepDM) scale [15], the Single Item Literacy Screener (SILS) [16], and the Single Ease Questionnaire (SEQ) [17]. The PrepDM scale measures the participant's perception of how useful our DA was in preparing him or her to communicate with his or her provider about his or her decision about the corrective surgery [15]. The SILS assesses the participant's health literacy [16]. The SEQ measures how difficult a participant found a task [17].

Results

Demographics

Ten participants participated in each phase of testing, for a total of 20 unique participants (Table 1).

Phase I scores

Phase I's acceptability and usability scores were high. The SUS mean score was 75.3 (out of 100; SD 5.8), which is considered above average [11,18]. Using the DAAS, 70% of participants found the DA's information "about right" or "much more than wanted"; 90% found its length "about right," 90% found "most things were clear" or "everything clear," and 60% found it to be "completely balanced" in terms of making a decision (i.e., surgery or no surgery) [12].

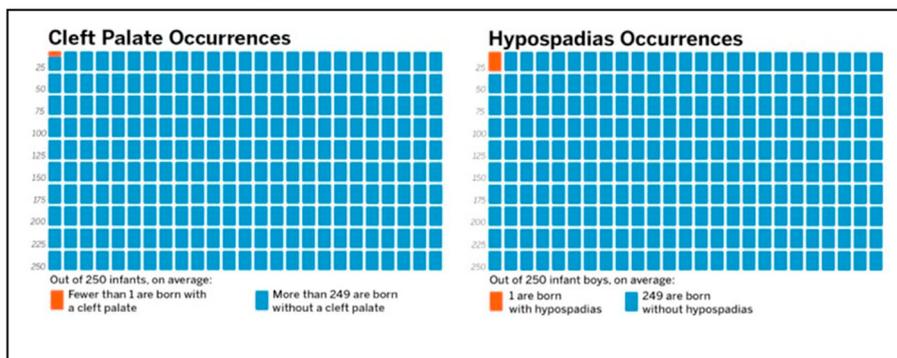
Phase 1 qualitative results and revisions

Based on participants' feedback in phase 1, changes were made to the DA. The following section details the themes that emerged in the analysis of the qualitative interviews and the subsequent changes.

Our analysis found four areas of revision: (1) VCM, (2) "Homepage," (3) "No Surgery" webpage, and (4) icon arrays on the "Hypospadias" webpage. First, the VCM was confusing and not helpful, because participants expected the quizzes to produce recommendations or answer specific questions. There was a discrepancy between the parents' expectations and the VCM's function. Participants also reported a lack of information, resulting in decisional conflict. We redesigned the VCM to be implicit rather than explicit (Fig. 2) [10]. We created a list of questions to serve as a conversation guide with a provider and labelled the webpage, "Think It Through." We also designed a webpage, "Pros and Cons," to summarize the advantages and disadvantages of surgery as an infant, versus no surgery, versus delayed surgery as an older child.

Second, participants thought the "Homepage" did not resemble a traditional website homepage and was uninteresting. Many voiced concerns about the placements of pictures and too much text, so we updated the "Homepage" structure. We added a slideshow of pictures with

A Icon Array



B Icon Bar Graph

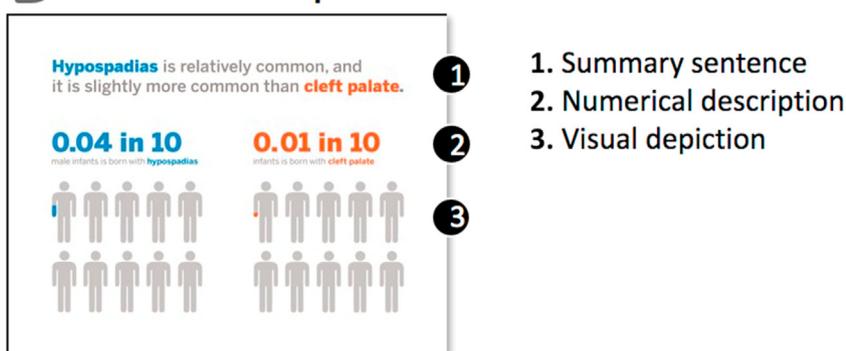


Fig. 1 Using data visualizations to explain risk. *Note.* Participants provided mixed feedback about the icon array in phase 1 testing, so we included an icon bar graph in phase 2 testing. An icon bar graph included a summary sentence and a smaller dominator.

clickable links, included a definition of hypospadias, and wrote descriptions about each webpage.

Third, participants found the “No Surgery” webpage to be text heavy with too many perplexing statistics that contradicted the “Homepage” information. Also, participants thought the “Homepage” did not clearly explain why no surgery is an option. This may support why 40% of participants viewed the DA as not ‘balanced’ in terms of treatment options. Therefore, we removed most of the text and created illustrations to explain important information and address confusing terminology.

Lastly, we used icon arrays to demonstrate how common hypospadias is compared to other health conditions. Participants found the icon arrays to be unclear; so, we removed the icon array illustrating the twin birth and C-section but kept the one comparing hypospadias and cleft palate. We designed an icon bar graph illustrating the same statistical information as the icon array but used a smaller denominator to reduce the amount of icons presented. The icon bar graph was placed underneath the icon array on the “Hypospadias” webpage.

Phase 2 scores

Similar to phase 1, phase 2’s usability and acceptability scores were high. The PrepDM’s mean score was 86.8 (out of

100 points; SD 6.7), which indicates a high perceived level of preparation for decision making [15]. In measuring health literacy, 50% participants never needed help reading instructions, pamphlets, or other written material from their doctor or pharmacy. Forty-percent rarely needed help and 10% needed help sometimes [16]. SEQ’s mean score was 6.7 (out of 7; SD .5), which indicates that participants found it very easy to navigate the DA to find specific answers [17].

Phase 2 qualitative results and revisions

Our qualitative analysis found three prominent revisions: (1) data visualizations, (2) navigation bar for the VCM, and (3) “Surgery Day” webpage to include information about general anesthesia. These changes are in addition to the phase 1 revisions and are described in this section.

First, there were mixed opinions about the data visualizations. Six participants liked the icon array and four liked the icon bar graph. Participants who liked the icon array found it easier to understand because shading was apparent and quantifiable. Others were unfamiliar with the format and did not like the amount of “blue boxes” and noted the small font. Participants explained the icon bar graph’s denominator was easier to comprehend because it was smaller (10 versus 250). To improve the icon bar graph’s likability, participants recommended the font be bigger,

Table 1 Demographic characteristics of study sample, phase 1 and 2.

Variable	Number (%)
Mean age (SD = 3.98)	33.4
Sex	
Female	12 (60)
Male	6 (40)
Race	
Black	2 (10)
Caucasian	16 (80)
Native American/Alaskan Native	1 (5)
More than one race	1 (5)
Marital status	
Married	15 (75)
Single	5 (25)
Education	
Some high school	1 (5)
High school diploma	4 (20)
Some college	2 (10)
College degree	10 (50)
Postgraduate degree	3 (15)
Median income by zip code	
35,000–49,999	5 (25)
50,000–74,999	12 (60)
75,000–99,999	0 (0)
100,000-more	3 (15)
Insurance type	
Private – Anthem, Aetna, TBC	10 (50)
Public – Medicaid, Children's Special Services, TBC	6 (30)
Self-pay	3 (15)
Unknown	1 (5)
Device used	
Desktop	1
Laptop	4
Smartphone	2
Tablet	3
Health literacy^a	
<i>How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?</i>	
Never	5 (50)
Rarely	4 (40)
Sometimes	1 (10)
Often	0 (0)
Always	0 (0)

^a Health literacy and device type was only assessed with phase 2 participants.

the statistic be a whole number, and there be more visible shading to represent the small percentage. Thus, we changed the icon array's text, colors, and increased the font size. The icon bar graph was removed from the DA.

During the scavenger hunt, participants had difficulties navigating to the "Pros and Cons" webpage because it was listed under the "Activity" menu tab, which was not intuitive. Therefore, we removed the "Activity" tab and added two separate tabs, "Think It Through" and "Pros and Cons,"

to the menu bar. The tabs included the VCM, which participants expressed that the exercises would assist them in their decision making process, facilitate a conversation with the provider, and feel informed about hypospadias (Table 2).

Next, we added more information about general anesthesia to the "Surgery Day" webpage. We did not ask any questions about the anesthesia, but, 7 out of 10 participants expressed concerns. Due to the theme's prevalence, we added general anesthesia information to the "Surgery Day" page.

Participants found the testimonials valuable and informative. Many participants commented that they would watch all of the testimonials if there was time during the interview. Participants often noted that they related to the testimonial experiences and found it relieving to hear from other parents. One participant stated, "They [Family Stories' parents] wanted more information beforehand. So that's me right now. So that's one reason why I have agreed to do this, so that I can get a better understanding of his condition." Further, participants related to the parents, because they, too, were worried about the future and wanted more information. Participants felt reassured by listening to others. The most popular testimonial featured a parent who chose no surgery for her son. The other top two testimonials featured couples who chose surgery for their sons, who had mild (distal shaft) cases. They discussed what the day of surgery and recovery was like. All participants found the testimonials were the appropriate length and kept their attention.

As the phase 2 scores indicate, we received positive feedback about the DA. One participant commented, "If I had been able to access this website when I was making my decision, it would have been so much easier to decide, because all the information about everything is one page." Another participant stated, "I would've liked to see it sooner ... it provided more information than I had before or after the visit with my son's urologist." The positive feedback illustrates how the DA fulfills participants' need for information about hypospadias surgery to make an informed decision.

Discussion

We implemented an iterative, two-phase process to test a hypospadias DA's acceptability and usability. This iterative design methodology allowed us to validate the basic concept of the DA and address any major usability and acceptability issues prior to pilot testing in a clinical setting [19].

After phase 1, participants strongly agreed that they felt confident using the DA. Many participants thought that most people would learn how to use the DA quickly. Although there was general acceptance, participants provided suggestions for revisions. Prior to phase 2 testing, we revised: (1) VCM, (2) "Homepage," (3) "No Surgery" webpage, and (4) data visualizations.

The revisions proved to be valuable for phase 2 testing as participants responded positively, specifically about using the DA to communicate with their provider and making a decision that aligns with their values. The DA offers pre-operative education to reduce parents' decisional regret

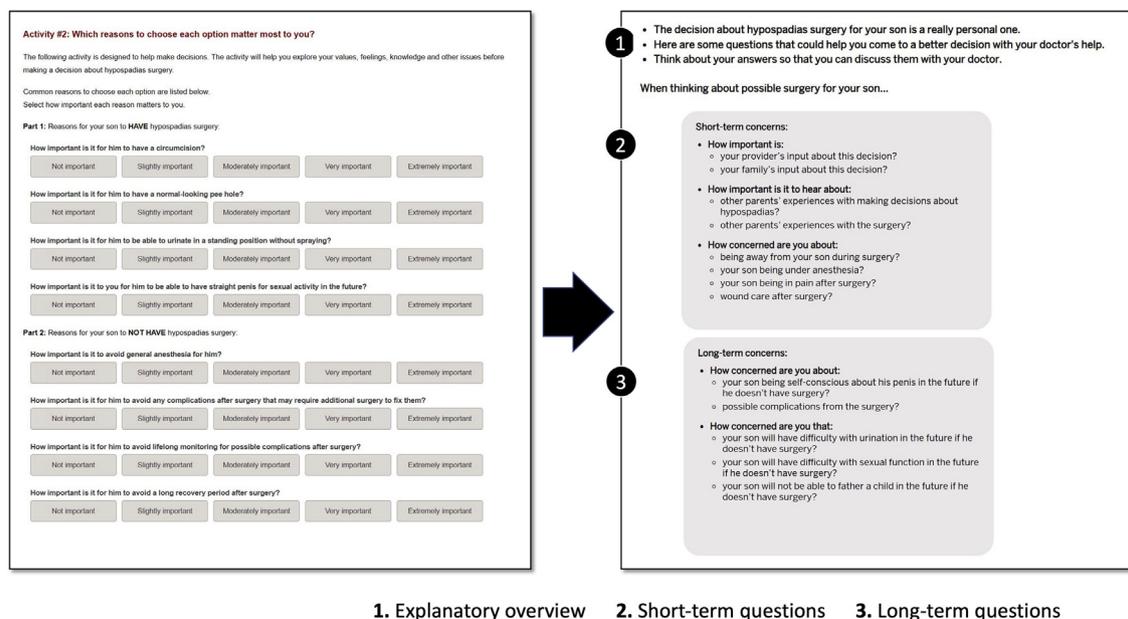


Fig. 2 Revising value clarification methods from phase 1 to phase 2. *Note.* The illustration on the left is from phase 1, and it was an interactive activity the participant completed. On the right is the revised version, and it was tested in phase 2. This activity was implicit and included an explanatory overview and short-term and long-term questions.

and decisional conflict; thus, we plan to evaluate these outcomes in our future pilot test [20,21]. Additionally, many participants expressed that they wished they had the DA before making their decision, because they felt more informed.

All participants found the testimonials to be helpful, because they featured parents' knowledge, beliefs, reasoning, and emotions regarding their decision. Concordant with existing literature, patient narratives provide emotional and social information that may not be regularly found in resources [22]. Because health narratives help patients recall information at a later time, our DA could help support parents in having a discussion about their decision with their child's urologist [23–25].

Additionally, participants believed that if they had the DA prior to making their decision they could prioritize their concerns and develop questions for their provider, partner, etc. Many expressed the same concerns that were included on the "Think It Through" and "Pros and Cons" webpages; however, participants appreciated having prompts readily available. Having information presented in a concise and organized manner helped participants navigate the DA and get the answers they needed to make a decision.

Prior studies of DA development/acceptability testing in urology have focused on adult urologic conditions/procedures, such as small renal masses, urinary diversion, prostate cancer treatment options and benign prostatic hypertrophy [26–30]. Similar to our study, majority of patients and urologists who participated in the alpha-testing of the urinary diversion and small renal mass DA's responded favorably [29,30]. Most reported that the DAs were well-balanced, adequate in length, included appropriate language and would be useful tools for future patients facing the respective decisions. Reported strengths of the urinary diversion DA were the plain language, descriptive figures, and overall concept [29]. An important point among

urologists in both studies was the inclusion of additional surgical options (e.g., continent cutaneous diversion and partial nephrectomy, respectively) [29,30]. Narrative feedback from patients focused more on clarity of language. Images and pictorial diagrams were described as strengths by both groups. We received similar feedback from pediatric urologists in a prior phase of our study, who suggested a cartoon-like surgery storyboard depict to steps of the procedure [5]. Interestingly, they recommended simplifying the procedure, focusing on one-stage and distal repairs rather than adding treatment options.

One limitation of this study is the sample's lack of diversity. Through purposive sampling, we attempted to contact participants who belonged to underrepresented groups. Due to the small sample size, not all views may have been expressed. Also, participants were highly educated. The high education level could have led to an overestimate of the DA's perceived usefulness and acceptability. Those with a high education level may have sought out other resources to help them navigate their decision about surgery; thus, viewing the DA could have confirmed previous knowledge. Lastly, the sample included participants who already made their decision about hypospadias surgery. Thus, participants may not have considered some of the emotions they felt when they made the decision in real-time. Although participants reflected on their experience, many commented they wished they had the DA prior to making their decision.

To further this research and address the noted limitations, the DA should pilot tested in a clinical setting. Researchers should consider assessing the parents' knowledge about hypospadias and decision about treatment at multiple time points to determine if the DA assists in SDM and addresses the outcomes of decisional conflict and regret. To include more diversity in a future sample, linguistic and cultural adaptations should be made.

Table 2 Participant quotes about value clarification methods, phase 2 only.

Theme	Think it through	Pros and cons
Assist in the parent's decision making process	I think it'd be really helpful if I haven't made my decision already, just became the most common questions that you might want to ask are right there for you to ask. It's so easy to forget what you're going to ask you provider when you first go in there, just because you're new to, it's probably first time you've ever heard about it and don't know what to ask. (F, #1)	It would help you with making your decision. It's got all of your positives and your negatives right there. So, when you're weighing your options you just have all your information in front of you. (F, #9)
	This page could be a potential decision maker. If you were to print out and ask these questions and see how you feel, because everyone might feel different about it and this might make your decision. (M, #5)	I think this is probably if you've looked into this condition, this is going to be kind of where you're going to make your decision. It's going to be helpful in laying out that and just talking through that process. It's also going to give you kind of the chance to really finalize what those most important questions you have for the doctor are if you want to consult them before making a final decision. (M, #10)
Facilitate conversation with the provider	I think this would be helpful because sometimes you don't know what to ask when you go to doctor's appointments. So, I think this is helpful to look over and have this information and that way you can know what kind of questions to ask. (F, #7)	To go over what they [providers] think any cons could be, pros could be, if there's anything else they could add to help me with my decision. (F, #1)
	It shows maybe some of the questions you should be having that you're not thinking about. So, it is I mean, it's interesting, especially if this is pre-consultation, it shows some of the things maybe you should be heading into the surgery and talking to your physician about. (M, #2)	You can share a print activity and discuss with the health care provider ... I would definitely write down some questions or take a question or two and then ask my doctor about it. (F, #4)
	"Yeah...by using some of the questions that I read here, I would ask his urologist and get the urologist's actual feedback of his answers to these questions. (F, #5)	I think if I had an appointment coming up I think this kind of gives you a frame to know a little bit about the surgery and you could ask more specific questions or maybe if you're leaning one way or another, you can ask for the physicians input as well. (F, #7)
Feel informed about the condition	I would go through this with my husband at home before hand and then whatever questions we have, I'd bring those to him [provider]. (M, #3)	Just as before I'll would use it as ... conversation starters, like asking him what it would look like with the surgery, how he would be and then asking the urologists about what's the possible life he would have without the surgery. (M, #5)
	I guess, having already knowing how common it actually is, kind of puts the mind at ease a little more. If I didn't have that information already, this would be helpful page because I could kind of think about if it was really necessary to get the surgery. (F, #6)	I would learn about the benefits of having the surgery ... information about surgery, like the good things that would happen for surgery and the possible bad things that might have been or not ... so good things that might happen. (F, #8)
	I'd be able to talk with my husband about these things and figure out if we covered everything before we made a decision. (F, #4)	When I was looking through before I just hadn't gone to this tab, but this is something that I would specifically want to see. (F, #7)

Conclusions

To our knowledge, this is the first parent-centered DA prototype that has been developed and tested for hypospadias. Participatory research methods, such as “think aloud,” may be helpful when designing and testing DAs as they privilege the patient’s experience [9]. Overall, participants found the DA informative and valuable in understanding hypospadias. Using our DA created a high perceived level of preparation for decision making.

Funding

This study is funded by a grant from the National Institutes of Health-National Institute of Diabetes and Digestive and Kidney Diseases (1K23DK111987-01). The preparation of this article was also supported in part by Research Jam: Indiana Clinical and Translational Sciences Institute’s Patient Engagement Core (PEC) through an award from the National Institutes of Health, National Center for Advancing Translational Sciences, Clinical and Translational Sciences Award [Award Number UL1TR002529].

Ethical approval statement

This research study was approved by Indiana University Institutional Review Board (#1511846401).

Conflicts of interest

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

Acknowledgements

The authors wish to thank the Pediatric Research Network (PResNet) of the Department of Pediatrics at Indiana University School of Medicine (Cathy Luthman, Vickie Cater, Elaine Cuevas, Ann Clark, and Whitney Fishburn) as well as Elhaam Bandali, Lauren Snodgrass (Urology) and Lisa Parks and Brandon Cockrum (Research Jam) for assistance with website design, recruitment and data collection, project management, and data management. The authors also wish to thank the Child Health Informatics Research and Development Laboratory (CHIRDL) of the Department of Pediatrics for assistance with website development.

Study data were collected and managed using REDCap electronic data capture tools hosted Indiana University School of Medicine. REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources.

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