



## Parental experience and understanding of parent-provider discussions of treatment for infants with ureteropelvic junction obstruction

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### ABSTRACT

**Objective:** The purpose of the current study was to understand what families identify as necessary information to guide decision-making in the treatment of their child with UPJO.

**Methods:** We conducted semi-structured interviews with parents of children with UPJO using phenomenological methodology. Data were systematically analyzed according to principles of thematic analysis, using a team-based inductive approach.

**Results:** 32 parents were interviewed. Findings are organized by three major themes including barriers to meaningful participation in decision making, logistical aspects of the decision, and psychosocial aspects of the decision.

**Conclusion:** These findings suggest the need to increase parent education and understanding around medical and surgical decision-making, and the need to enhance psychosocial support for more meaningful parental engagement in the surgical decision-making process.

**Practice implications:** The findings from the interviews highlight the importance of caregivers needing clear and accurate information in order to engage in meaningful discussions related to surgical decision-making for decisions around surgery for UPJO treatment.

### 1. Introduction

Ureteropelvic junction obstruction (UPJO) is a common condition affecting 4,000 – 10,000 infants annually across all strata [1,2]. The goal of surgical treatment of UPJO is to minimize the risk of kidney damage associated with obstruction, which may occur in 30-60% of infants with high-grade hydronephrosis [1-4]. However, the benefit of early surgery compared to observation and potential later surgery to preserve kidney function has not been well-defined and evidence-based guidelines for treatment are lacking. Furthermore, the decision for early surgery is not without risk. Infants treated surgically are at higher risk for readmission and reoperation [5]. Early surgery also raises concerns about neurodevelopmental effects of anesthetic exposure [6-8].

Due to the lack of clear data to guide recommendations, surgeons tend to rely on their own experiences when deciding whether and when surgical intervention is appropriate [9], with surgical rates varying greatly independent of disease severity in published studies [8,10]. A recent study shows that parents and surgeons both rely on these individualized surgeon recommendations to guide treatment

choice for UPJO [9]. However, little is published on the actual impact the surgical decision has on families.

In other settings, tools help patients, their families, and surgeons communicate clearly before surgery so that patients and families better understand a surgeon's recommendations and the effect surgery (or a decision to wait to have surgery) will have on their lives. Yet, while family centered care, which involves treatment planning featuring a partnership between the family and the medical team, is recommended as a best practice option regarding treatment choice, it is often insufficiently implemented [11].

Families offer unique perspectives that can help medical teams more accurately and sensitively communicate treatment choices and expectations so that patient/parent understanding vastly increases. If the families' perspectives are better understood by medical teams, families will be able to make more informed decisions based on the lived experiences of previous families that have gone through UPJO treatment. Moreover, in the spirit of incorporating family centered care into their practice, providers would benefit from augmenting their recommendations with information identified by parents as impacting their understanding and ability to make meaningful decisions; such a tool would mean that impactful family centered

Abbreviations: UPJO, Ureteropelvic junction obstruction.

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care could be more successfully implemented. The aim of the current study was to more deeply understand factors associated with the decision-making process for parents of children with UPJO.

## 2. Methods

### 2.1. Study Design

To understand parent perspectives on the practical, logistical, and emotional aspects of decision-making related to UPJO treatment, we analyzed parent interviews previously conducted as part of a qualitative study of parent and surgeon perceptions of the surgical decision-making process.

Phenomenological methodology was used to garner information about the lived experiences of parents of children with UPJO. This methodology allows for understanding parental perspectives, without predetermined assumptions, regarding their experiences. The analysis process included the following: identification of key points in the data through the use of codes, grouping of coded data into related concepts and themes, and integration of codes to develop a theoretical model that is then evaluated and modified based on subsequent gathered data. This methodology was chosen because of the primary purpose of the study: to better understand the experience of parents and caregivers of children with UPJO; to develop targeted resources and educational materials to support shared decision-making; and to inform future quantitative studies in this population. One limitation to a phenomenological approach is researcher bias. To minimize this limitation, the research team was interdisciplinary, and a team-based inductive approach was utilized during data analysis [12].

### 2.2. Participants and setting

After institutional review board approval was obtained, parents of children 6 months to 2 years with grade 3 or higher hydronephrosis were invited to participate in an interview. Study inclusion criteria were as follows: a) the child had undergone imaging concerning for UPJO, b) the child had been treated with pyeloplasty or observation for at least one year, c) if a surgical intervention had been completed, the child had experienced at least 3 months post-operative follow up, d) the child was receiving care by a provider in the Children's Hospital Colorado practice, which is an academic medical center with 6 urologists and 4 advanced practice providers on staff seeing patients with UPJO during the time of the study. Eligible parents were invited in-person, via mailed flyers, and via telephone. Parent interviews were conducted in-person or via telephone based on parent preference. Purposive sampling was utilized to ensure diversity of parent experience (treatment modalities - surgery vs. non-surgery) and to align demographic factors with the patient population at the hospital (gender, race, ethnicity, distance from the hospital). Participant recruitment was discontinued when thematic saturation and adequate diversity of interviewees (mother, father, other caregiver) had been achieved.

### 2.3. Data collection

Semi-structured interviews were conducted by one of three interviewers (MAM, MKH, CG) with training in qualitative research. Semi-structured interviews were selected to allow the interviews to be focused and organized while allowing the research team to explore pertinent ideas elicited from parents during the interviews [13]. Spanish interviews were conducted with parents whose preferred language was Spanish. Interviewers had no personal or professional relationships with the parents. Interviews were recorded and digitally transcribed. In addition, Spanish interviews were translated into English after transcription. The interview guide was developed based on shared decision-making literature and urology literature. Emphasis was placed on parental perspectives and their reactions to a child's diagnosis, their understanding of their child's diagnosis and treatment options, the parent's relationship with the medical team, and the role the parents played in the decision-making process. Questions were open-ended to avoid bias and to permit participants to describe

experiences from their own perspectives. Additional follow-up questions were added to clarify parents' specific experiences. Field notes indicated location, length, and behavioral observations.

### 2.4. Data analysis

Data were systematically analyzed according to principles of thematic analysis, using a team-based inductive approach [13,14]. The first phase of data analysis involved the team members reviewing transcripts independently. The team then collaboratively met to develop an initial codebook. The team applied the codebook to a subset of transcripts, adapting and modifying the code and code definitions as needed. This process continued until a final codebook was agreed upon. The team then applied the final codebook to the remaining transcripts. Coded data were entered into Atlas.ti for data management. All coded data were analyzed for emerging concepts and themes that fit within the research questions and parent responses. Overall trends, patterns, clusters, relationships, exceptions, and alternative explanations were checked iteratively across the coded data [14]. Finally, member checking with a parent stakeholder advisory committee was conducted; these parents participated in the study and were invited to serve on the advisory committee as they were representative of the larger study sample.

## 3. Results

### 3.1. Participants

Fifty parents met the inclusion criteria for the study. A total of 32 parents were interviewed for the study and 3 eligible parents declined to participate. The additional 15 parents eligible for the study were not contacted as thematic saturation was reached and no further interviews were deemed necessary. Table 1 for parent characteristics.

### 3.2. Key themes

Findings are organized by three major themes: (1) Sources and Gaps in Information During the Decision-Making Process, (2) Logistical Aspects of the Decision, and (3) Psychosocial Aspects of the Decision. See Table 2 for themes, subthemes, and representative quotations.

#### 3.2.1. Sources and gaps in information during the decision-making process

3.2.1.1. *Resource gathering prior to decision.* Parents discussed their concerns about accurate information to help aid in the decision-making process and wanting to gather some preliminary information before starting their own research. One parent commented, "The nurses put the information regarding what the actual diagnosis was and then I just kind of did a little bit of research as well." (ID 2) Another parent commented, "I was worried about getting misinformation. So, I just always wanted to wait and hear what the doctors had to say." (ID 23) However, many commented on the lack of available resources:

**Table 1**  
Parent and caregiver demographics.

Parent Characteristics	N (%)
Patient sex, male	24 (75%)
Distance to hospital, $\geq$ 50 miles	12 (37.5%)
Surgical intervention	16 (50%)
Primary spoken language is English	29 (90.6%)
Hispanic ethnicity	9 (28.1%)
White race	26 (81.25%)
Interviewee	
Mother	23 (71.9%)
Father	3 (9.4%)
Both mother and father	3 (9.4%)
Other relative or guardian	1 (3.1%)

**Table 2**  
Key themes.

Theme	Quotes
Sources and Gaps in Information During the Decision-Making Process	<p>I think we certainly did the typical Google the terms to find some more information about what we were talking about. I think I had looked up the National Kidney Foundation website for a little bit more clarification about what hydronephrosis was. Yes, we certainly did a little bit of self-education outside of what we had been given for information. (ID 21)</p> <p>Yes, although - I mean, I Googled a little bit, but mostly I went onto the Children's website because they had a lot of information on their own website about what the condition was and what to expect from it. (ID 6)</p> <p>I wish I would've been handed that document at that point because I did all of that back research on my own ... but here was this fabulous diagram and document that was like, "Oh, I hadn't seen this. This is the first time I'm seeing this. Why is this the first time I'm seeing this?" (ID 17)</p>
Information and Resource Gathering	<p>Definitely get a doctor that you feel comfortable with, and don't be scared to ask questions. I feel like we've always been those patients that just ask eight million questions, good or bad, I don't know. I think we've kind of made ourselves comfortable. We never left feeling unsure or questioning about the problem, or the procedures, or the aftereffects. (ID 9)</p> <p>He would draw pictures and visually, and verbally walk us through our procedure options. (ID 7)</p> <p>Yeah. He always showed us the x-ray, or the ultrasound, and walked us through exactly what he was seeing, and why he was coming to the decision that he was coming to. We never felt like there was some just, one dang decision happening over here, these unclear pieces of evidence. We always knew what his evidence was in making his decision. (ID 8)</p> <p>Yeah, I think because the nature of our visits are, "Hey, let's monitor this and see." I think he must have a diagnosis, because they have talked about surgery potentially being an option down the road. I don't think they would be talking about that without a pretty clear idea of what was going on. (ID 17)</p> <p>I trusted him after he explained everything. When I left there, I wasn't concerned. (ID 13)</p> <p>Here's what the results said from the test, and this is what I would recommend." I agreed with his suggestions, so we went with it. (ID 1)</p> <p>I guess just, you know, trust what the doctors say, and if you don't feel like the answers are good enough for you, do some research on your own, but, um, no, I guess just trust that they know what they're doing, I guess. (ID 30)</p> <p>Listen and trust your doctors. They're there to help you and provide the best care that they can for your kiddos. And ask questions. (ID 5)</p> <p>No, just she explains it to where you can understand it and that was helpful. And obviously she's the doctor, so we want to take her word for it. She's the one who knows what's going on and we don't. (ID 2)</p> <p>He knows how to express his point in a way that the patient is, and the patient's people, are going to be able to kinda' understand what is happening. I think I've always felt that he has known what his plan is before he comes in, which is a good thing for us. (ID 9)</p> <p>I don't think there were, like, a lot of options for us in the first place, you know so we kind of just - we kind of just, you know - we-we came into it not knowing much so we've really just trusted our doctor and to, uh, you know to guide us in the right direction. (ID 63)</p> <p>I felt like he respected us as intelligent human beings, that would be able to go home and look at the pros and cons and come up with our own decision. (ID 10)</p> <p>Within minutes of them talking I felt better because the first words out of their mouth were, "This is fine. I want you to relax. Your baby's gonna be fine. You're gonna be fine." I mean, it was just the most calming words, and I'm so glad he said that because everything was fine. It was a totally normal pregnancy, and he was totally normal. In fact, we didn't even tell our parents about it because we really wanted everything to be treated as if it was normal. (ID 6)</p> <p>We want to leave the expertise in the doctor's hands, but just so we have more of a place at the table there. I think ultimately, he's explained it great to us. It's just it's probably more of an assertiveness and us making sure that we understand everything. (ID 21)</p> <p>I'm very thankful that we finally found Children's and found a place that eased our minds and kind of slowed down the panic train and gave us some perspective and allowed us to truly enjoy the pregnancy, as much as pregnancy can actually be enjoyed. (ID 12)</p> <p>I didn't need anyone to tell me what could be, what would've been. I just wanted you to tell me, "this is what it is" "this is how we're gonna fix it, and that's it", and that's all I wanted. (ID 22)</p> <p>It wasn't until I was actually able to see the specialist that we were able to - he was able to actually explain everything and then calm me down. (ID 11)</p>
Reliance on surgeon during the decision-making process	

Table 2 (continued)

Theme	Quotes
	Yeah, as my husband was saying, just, you know, having, you know, like doctors that take the time to, you know, explain things to you, you know, the parents. You know, that makes a world of difference. It does when you - when you feel like you know, and you're - you leave there feeling comfortable. (ID 63)
	Um, I mean, everybody was really great. Like, obviously, we were super nervous, and they definitely helped us feel better, totally - us not being able to feed him for, like, four hours. (ID 23)
Education about care after surgery	And that was - that was scary for me because when I go to change his diaper and his stint is laying in his diaper and I'm freaking out, and it's all red around the incision and I haven't seen the doctor, and I haven't seen any of the - I didn't know what to do. (ID 22)
	I think one of the things that I've worried a lot about is whether this medication or that medication will affect his kidneys. I kinda wish that there was a list that they gave you ... I've always wondered like can you - can I give him this? (ID 21)
	Personally, I would have made my husband stay with me at the hospital through the surgery instead of coming home. We did have a toddler, and we do have a toddler. So, we felt that we wanted to try to keep things as stable as possible for him, too. I really needed someone there to help me that night. (ID 3)
Logistical Aspects of Decision Acknowledgment of a decision being made	Um, I would say easier because the fact that we had a choice, you know, to wait - you know, it wasn't like a rush. "Oh, my goodness, we better fix this problem right now." (ID 63)
	Yeah, I guess it's going back to the conversation, just spelling out a little more in detail why this pursuit of just waiting and seeing is the best. I think there's probably ramifications for doing both in the decision to wait more. I think that will be the information, spelling it out a little more. I think he spells out the physiology really, but not necessarily the decision making. (ID 17)
	I appreciated being able to have time to, I don't know, as if I was going to be a doctor, and make my own choice. I felt like he respected us as intelligent human beings, that would be able to go home and look at the pros and cons and come up with our own decision. (ID 20)
Waiting game	I think that sums up where we've been just emotionally in this whole thing, just waiting for the definitive answer. (ID 17)
	We were tracking that pretty early in his birth... Basically, since his birth, that's sort of been the story with him is just to keep monitoring, keep monitoring, keep monitoring, but no real movement one way or the other. It doesn't seem to be getting worse, and it's also not getting any better. (ID 12)
	I think they took the time and were patient enough to watch and wait and didn't do anything that wasn't necessary. We didn't just jump into surgery. I liked the more conservative watch-and-wait approach. (ID 5)
	A lot of that was just we were just watching and waiting and just making sure it didn't get worse, and it got better. (ID 63)
	Um, it was just months of, you know, waiting. And not knowing what was going on, really. (ID 23)
	So, we had the multiple ultrasounds, the imaging. We had the voiding cystogram, VCUG, and then we also had - I think we had a - oh my gosh, it was a forever scan, x-rays for an hour. It's a MAG3 renal scan. I don't remember what that one was. So, we had one VCUG and then that forever x-ray, the renal scan, and then just the ultrasounds. (ID 15)
	Let's see, I guess expected and wishful thinking, I was hoping that it would continue to improve and that we wouldn't have to go the surgery route. I guess as far as what I expected, it was great that it continued to improve. I don't know. I was more or less hoping that we could just continue to watch and wait, and it would get better, and so it was nice when that actually did happen. (ID 18)
Psychosocial aspects of the diagnosis and associated decision-making Emotional reactions	It's just like so scary, even as an adult. Like, I don't really wanna have surgery, so to have such a small baby have surgery was something that I was hoping to av-avoid. (ID 32)
	I actually didn't know what to expect...I had so many emotions goin' on, um, not only because, you know, I just had a baby, but now, I have a baby that has somethin' wrong with his kidneys. So, I was just - my biggest thing was I just thought the worst and I couldn't prepare myself for, you know - it could be something very, very minor. So that's pretty much - I mean, that's what went through my head. (ID 22)
	I was so like-like shocked, I think that at that time that like I was like, oh my gosh, my baby's gonna have to have surgery um possibly. (ID 28)
	But at this point I'm just so happy that it's over. (ID 3)
	Just breathe. It's gonna be okay. It seems like it's a lot to have a kid go through, but I could tell that my son was in pain and now he's been a completely different child since his surgery. He's happy. He doesn't stop. (ID 15)

Table 2 (continued)

Theme	Quotes
	<p>Why are these really important doctors giving up their day or their whatever to sit down around this conference room table to talk about our baby? At the same time, when I walked in that room, it scared the crap outta me. That was the moment that panic really hit. (ID 6)</p> <p>I was very relieved driving home after our 11-day appointment, having had to do nothing other than an ultrasound and knowing that I got to take my baby home and let him grow and get a little bit stronger before the potential of anything happening. (ID 19)</p> <p>I freaked out. (ID 4)</p> <p>... I was worried. I was afraid that, you know, it was gonna be bad, you know. I was expecting bad, terrible news, you know so I kind of went in there kind of, you know, scared to hear what. (ID 63)</p> <p>I guess I was nervous because it's my child and they're saying something's wrong with him potentially, but yeah, I think she handled everything appropriate and taken what was in the best interest for [child]. (ID 23)</p> <p>Both my husband and I had tears in our eyes...cuz her breathing did get kinda funky. (ID 13)</p> <p>you know, and so the stress of having, and, you know, the other piece of it is I had a - I had him in a birth center, and I'm not really a big fan of hospitals...being in the hospital is - I'm not gonna say a trigger for me because I'm pretty mature and grounded and, you know, all of that - but was very stressful to have just given birth, then to have to bring for the... (ID 31)</p> <p>Her dad hides it a little better, but I cried. I cried as soon as they took her from me. No, I didn't. I sat there, and I worried. (ID 29)</p> <p>You know the scary part about like having a VCG from my perspective was this was a tiny baby and they're gonna put him to sleep and they're you know. It just seemed too scary for me, but I would tell - I actually do have a girlfriend who just had a baby and the baby they thought had a kidney problem... My advice immediately to her was the same thing, but she was scared to death.... and I'm like, "You've got to do it. Do not wait." (ID 18)</p> <p>It started to seem like my daughter was falling into a very rare category, which was, again, alarming. Cuz I wasn't made to feel that way prior. It felt like, "It's not uncommon, but it's not super-common." (ID 14)</p> <p>Well, pretty much a wreck, and I think my husband was, too. It was a pretty short surgery. It was hard to - it's really hard to watch standing in the pre-op room, and you're watching them roll your baby off and he's crying 'cause he hasn't eaten since 4:00 in the morning. And then waiting was really difficult. (ID 3)</p> <p>Um, nerve-wracking. Um, I have never had surgery myself. (ID 28)</p> <p>Uh, terrifying. We were always scared that we were hurting them. (ID 10)</p> <p>I felt fairly relaxed and uh confident in the waiting process. (ID 30)</p> <p>mean, it's that gut-wrenching feeling that even in the advent of modern medicine, you're always playing the worst-case scenarios in your mind. I would say, surprisingly, I was much more calm than I anticipated I would be. My primary care physician had graciously offered that if he needed to write me a Xanax prescription during that time that he would be happy to do so knowing that - technically, I'm prone to a bit of anxiety - that would be an acceptable moment to take that if I needed it. (ID 21)</p> <p>Uh, I mean, obviously having a three-week-old having surgery was terrifying. (ID 23)</p>
Necessity of Social Support	<p>It's just a really strong support system between us two. (ID 17)</p> <p>I had his dad, my boyfriend, and then his dad's whole family and my whole family as well. They were very supportive and there if I needed. They came with me for surgery because my boyfriend could not as well, so they were there with me waiting. (ID 15)</p> <p>I had ultimately decided that... I was going to be able to handle this okay and especially with the familial support and the friends and family support that we had that I could handle that internally. (ID 21)</p> <p>... my sister-in-law is an anesthesiologist. It's what she does for a living and you know, I was not does she think, even her input it's not that she thinks it's horrible and that it's - but why do it if it's really not gonna help? You know, so it was kind of a joint family decision with an actual anesthesiologist's input, you know. (ID 18)</p> <p>I called friends that were doctors and talked to friends whose parents were doctors. (ID 16)</p>

(continued on next page)

Table 2 (continued)

Theme	Quotes
	So, like my best friend and my mother and my sister. (ID 24)
	So, I-I know our babysitter helped us out a lot. And my mom was here a lot to help us too. (ID 6)
	So, we had a lot of people in our corner, that's for sure. (ID 22)
	My mom was with me and she just automatically felt like he was going to be in good hands. (ID 2)
Coping Mechanisms	I guess in the back of my mind, I've always thought she'll be fine. I think that's true. If it's not true, nobody has ever indicated that to me. (ID 13)
	We did. We took a vacation cuz we didn't know how it was gonna' turn out, and we wanted her to be able to go to the beach, in case it went the wrong direction. (ID 9)
	From the beginning, I think I accepted, it is what it is. (ID 11)
	Um, well we are Christians, so we -we, uh, prayed and you know, I think sought comfort that way. (ID 28)

*"I wish we had a handout or something about what his specific condition was... I guess I wish I had more specific info that I could review and read over and know what exactly is this condition and what does it mean."*

(ID 3)

Parents commented that without accurate information, they started to "google" and had some misperceptions. One noted,

*"For two weeks we sat thinking that our child was gonna have to have their kidney removed and live with one kidney for the rest of their life. I mean, worse-case scenario, because we had no information. We were just working off of lay people tryin' to read WebMD."*

(ID 9)

**3.2.1.2. Reliance on surgeon during the decision-making process.** Parents discussed how they relied on their child's surgeon for education about the condition. Parents commented, "he was really thorough in his explanations" (ID 24); "he walked through the procedure and diagnosis as a very high level" (ID 44); and "they gave us all the information that we needed." (ID 6) One parent shared that their surgeon stated, "Well, we know she has it, but we can't really do anything at this age." (ID 9) That same parent reported that the surgeon was "walking through what the potential items it could be. Whether it was a disconnected ureter, whether the ureter's connected in the wrong place, whether it's reflux." (ID 9) As this related to decision-making for their children, parents had differences in their engagement in the decision-making process with their surgeons, some commented that they are:

*"just trying to get more information to where we put the decision into our hands. I know that feels kind of arrogant, because neither of us are licensed pediatricians. We want to leave the expertise in the doctor's hands, but just so we have more of a place at the table there."*

(ID 17)

Others relied on their own self-education, but ultimately, they said that the doctor "told us he thought surgery was the best option. And we didn't question that." (ID 3) Trust was, in the end, a major element of parental decision-making. One parent commented, "you have to trust them, but you also have to trust yourself." (ID 24) Another shared, "I just had to trust the medical professionals to do and tell me like the best thing. And I didn't have like knowledge to question their knowledge." (ID 7)

Parents shared that they relied on their surgeons for support and encouragement around their child's medical diagnosis. One parent stated, the doctor "was able to actually explain everything and then calm me down." (ID 22) Another parent shared,

*"We were extremely impressed with just how well he um talked to us about the problem, ... he was very kind and considerate, and uh didn't seem rushed or anything at all. He was willing to take the time to help us, explain, and reassure us."*

(ID 30)

Another parent commented on the interaction with the surgeon and stated, "he was very, very, very kind, very reassuring. Um, he actually helped make - you know, take my worries down." (ID 1)

**3.2.1.3. Education about care after surgery.** If the decision for surgery was made, parents shared that they wanted more details about what to expect after surgery:

*"One thing that I had noticed that I thought might be good feedback was the outpatient materials that we received when we were discharged to go home had a description of the surgery that he had had, of what a pyeloplasty was, and some fantastic diagram of what it would do, and how it would like, I just remember thinking, 'Well, they just did this.' At that appointment where he [the doctor] submitted that it was clear we need to do the surgery, I wish I would've been handed that document at that point."*

(ID 21)

Parents also discussed wanting to know what to expect from their child's symptoms and status after surgery so they could prepare:

*"He was so fussy, understandably, of course. It was just hard to not have another person there to give a little bit of relief when I felt like I needed a break or to just sleep for a few minutes. I think that's the biggest thing as far as after the surgery."*

(ID 3)

### 3.2.2. Logistical aspect of the decision

**3.2.2.1. Acknowledgment of a decision being made.** As described above, parents appreciated that they were given a choice about the treatment plan for their child; however, several commented on challenges or confusion associated with their decision if they did not pursue surgery initially "Honestly, I think I'm giving them too much credit. I don't even feel like it was a 'We need to keep waiting to see.' It was really just kind of blown off." (ID 13) Another parent stated,

*"I know surgery was offered or discussed, um, particularly with the first physician we were with. Um, but I - I think I'm more inclined to, you know, just be*

*a little more patient now and - and, uh wait, for more diagnostics and more answers and more time.*

(ID 26)

3.2.2.2. *“Waiting game”*. Parents discussed the challenges associated with the “wait and see approach” to care in UPJO. One parent stated, “Well, I think everybody kind of expects super-fast results on knowing exactly what’s going on with their kid, but I realized now that was unrealistic. Um, so, it was kind of just the waiting game.” (ID 29) Another parent referenced waiting on the definitive treatment plan stating, “just don’t get your hopes up...he’s born and now it’s gonna kick one way or the other.” (ID 17) Another parent commented,

*“I think surgery was always there, but, again, it was that, okay, we’ll wait and see approach, but we’ll just do extra monitoring in more timely increments to make sure that we’re keeping an eye on it. I think one of the things, for me, that further down the line when we actually got to the point where surgery was more on the table, it caught me off guard.”*

(ID 21)

Another parent discussed the waiting by stating, “they recommended that we just keep an eye on it and watch it, and it would probably resolve itself, and if not, we would be looking at some surgery to help clear up that situation.” (ID 30) Some parents appreciated the watchful waiting approach; one parent commented, “Why operate if we don’t have to? The urologist isn’t recommending it at this point. We’re not feeling worried about the condition at this point. Yeah, I mean, it seemed like a no-brainer to us.” (ID 6) The reality of “watchful waiting” was highlighted by two parents who stated, “There’s gonna be a lot more doctor visits...I didn’t expect it to go on this long with the sort of tone” (ID 17) and “it was more just an open-ended question mark, which I think we dealt with fine.” (ID 13)

### 3.2.3. Psychosocial aspects of the diagnosis and associated decision-making

3.2.3.1. *Emotional impact*. Most parents described fear as their most recognizable emotional response. Several commented on the fear associated with their child being “so little,” and one shared that, “it’s frightening ... when they’re so little ... They seem like, you know, they couldn’t handle anything.” (ID 63) Another shared, “It was nerve wracking just because he’s a baby.” (ID 2) Parents discussed how they experienced stress and worry associated with their child’s initial diagnosis: “I remember I started having an anxiety attack and was kinda saying, you know, like, ‘Chill yourself out so that you remember the things that they’re saying. Calm down. Take two deep breaths’” (ID 6) Others described feeling “terrified” (ID 3), “scared” (ID 24), and “stressed.” (ID 18) One parent shared, “we were in a high state of alarm.” (ID 29) Another noted, “I did have anxieties that I didn’t expect.” (ID 5) One parent even disclosed, “that was the worst experience I coulda probably went through” (ID 22) related to their child’s medical diagnosis.

Some parents described the learning about their need to make a decision about pursuing surgery for their child as “a little nerve-racking” (ID 22) while others had more mixed emotional responses: “I felt relieved but also scared, you know?” (ID 29) Other parents reported their attempts to remain calm; one commented that they “try to remain calm until you find out that it is really is something to be alarmed about ‘cause I definitely think that we had some moments of being really freaked out that in retrospect we didn’t need to be.” (ID 6) One parent shared, “I’m very thankful that it [referring to anxiety reactions] was as short-lived as it was in terms of the period that we were feeling really scared.” (ID 8) In contrast, several parents had less emotional reactions to their child’s diagnosis: “We never felt apprehensive or just unsettled” and “It’s been less stressful than I anticipated.” (ID 4)

3.2.3.2. *Necessity of social support*. Parents emphasized the importance of social support from their family and friends to assist in the decision-making process and in the care of their child with UPJO. In addition to their partner

or co-parent, most parents described utilizing their extended family for support: “I had a bunch of family support all the way from aunts to uncles to grandmas to grandpas and everybody.” (ID 2) The child’s grandparents were the most commonly referenced support: “We had lots of support from my parents” (ID 24); “my mom came in town” (ID 5); and “my dad actually came ... he came to the hospital that day to wait with my husband and I.” (ID 3) One parent commented, “We built a support system around us, because like I said, we didn’t know what - it was vague, going in blind, kind of thing, which was quite stressful.” (ID 9) Another referenced their entire family as “a circle of trust” (ID 13) that they can rely upon during stressful times. Another reflected on the helpfulness of their entire support system including their parents:

*“we are blessed to be able to have both of his grandparents here in Colorado with us. We have support on that front. We have fabulous neighbors who gave us many offers of help, mowing the lawn or feeding the cat kind of thing, just anything we needed. We had a tremendous amount of support.”*

(ID 21)

A few parents commented on how they did not share with their extended family members until they had greater clarity with the prognosis: “we didn’t even tell our parents about it because we wanted everything to be treated as if it was normal.” (ID 6) Finally, many parents discussed how they reached out to family members or friends with medical expertise for support: “I have a brother who’s also a doctor. I did call him too” (ID 13) and “I have a friend who is a doctor. We had talked to them about it, but it was kind of later in the process about treatment options, and what they thought was, you know, just their opinions, and things like that.” (ID 9)

3.2.3.3. *Coping mechanisms*. Parents shared their primary strategies for coping with their child’s UPJO diagnosis. Most parents described acceptance as their strategy for coping: “I think I have to just accept it” (ID 13) and “if we look at the big picture, we feel blessed in that it wasn’t more serious.” (ID 4) Some parents described avoidance as a strategy for coping; one parent illustrated this by commenting, “We tried not to think about it.” (ID 9) Finally, several participants described the importance of their “faith and beliefs” (ID 23) to support their coping: “I think our comfort came from people praying for her. We got it – that’s where we got a lot of our peace. Praying for direction for our doctors or whoever was overseeing her case.” (ID 4)

## 4. Discussion and conclusion

### 4.1. Discussion

This study serves as the initial needs assessment on the perspective of parents of children with UPJO and highlights parents’ perspectives on how best to help them navigate the complexity of care for children with this condition. It is clear from the findings of the qualitative interviews that families would benefit from additional support designed to enhance understanding and preparation. One possible way to address this finding would be to utilize a patient decision aid; patient decisions aids have been proven to help improve patient engagement in the decision-making process. Not only do they provide information about diagnoses and treatment options they also facilitate the alignment of care decisions with patient preferences and values [15,16].

Overall, parents and caregivers identified a deep desire to be involved in the surgical decision-making process, but there is a gap in their understanding about the overall treatment course and the logistical and psychosocial impacts of their decision. The first major theme that emerged in this qualitative interview was the theme of sources and gaps in information associated with meaningful participation in decision-making. The interviews highlighted that parents faced significant challenges with finding accurate information and resources related to deciding between surgery or observation. Oftentimes, the meant that families turned to the internet to obtain information that ultimately led them to inaccurate information. Thus, many parents shared that they just ended up relying on their child’s physician

for education and, ultimately, to tell them if they should pursue a surgical intervention or not for their child. At a first glance, this seems reasonable; however, this depended immensely on a family's trust of the surgeon, which often varied widely. Further, parents didn't just rely on their child's surgeon for guidance about the surgical decision-making process; our interviews also illustrated that parents turned to their child's provider for many other, things that may not seem typical requirements for a surgeon, things like encouragement, reassurance, and proving a calming effect related to their child's condition. Finally, parents of children that underwent surgery shared that they wanted more details about what to expect after surgery and how to manage symptoms post-operatively. While some parents shared that they were able to navigate and understand the condition with ease, most parents described significant barriers to their understanding.

The second major theme that emerged from the interviews with parents and caregivers of children with UPJO was the significance of the logistical aspect of the surgical decision. First, parents reported that they appreciated that they were given a choice to have the surgery or not, but many shared that they were confused about their path if they did not pursue surgery. Clearly, it appears that there is a knowledge gap in what the decision to pursue surgery or to not pursue surgery ultimately means to a child and their family to include a lack of knowledge about when a decision is needed. They often lack any understanding about the urgency of their decision. In addition, the interviews illustrated that there are significant challenges associated with simply waiting: parents commented often that it was extremely difficult to sit back and wait to see how the condition progressed or did not progress, that it was painful to wait and see what happened to their babies UPJO after they were born, and that it was also hard to do so by repeatedly coming in for multiple courses of imaging at incremental time points.

The final theme shared by parents was related to the psychosocial impact of their decision. Parents shared that they were emotionally impacted by their decisions about their child's health care needs, which can limit the ability of a caregiver to meaningfully engage in surgical decision-making process. Most parents and caregivers shared feeling fearful, stressed, and worried about their child's health condition. They also discussed how vital having support from friends and family was for both their emotional well-being, but it was also crucial for the logistical aspects of their child's health care needs. Finally, parents discussed the ways that they coped with their child's UPJO. Some focused on the acceptance of the reality of their child's condition while others avoided thinking about their child's condition altogether; others relied on their faith to support their coping.

The findings from the qualitative interviews highlight significant barriers to optimizing patient-centered care and shared decision-making in UPJO. To address the current barriers, we believe that tools to improve understanding—such as a decision aid—can be a way to support parental involvement in the surgical decision-making process in UPJO. In the adult setting, patient decision aids have been shown to improve patient engagement, patient knowledge about the diagnosis and treatment, and values-concordant decision-making [17]. Although the use of patient decision aids has been limited in the pediatric setting, studies suggest that patient decision aids improve knowledge, reduce decisional conflict, and increase parent satisfaction with the decision-making process [18]. However, to date, no patient decision aids have been developed or tested in parents of infants with prenatally diagnosed urologic anomalies, including UPJO.

Thus, we recommend the development of a patient decision aid for UPJO focused on the rich perspective of parents related to their experiences. Second, we recommend enhanced family support from psychosocial providers to address the emotional toll of a diagnosis of UPJO and the decisional stress related to treatment options. We believe future work on a patient decision aid will help to reduce some of the stress experienced by families; however, there continues to be a need for social work and psychology support in pediatric surgical decision making to support the emotional and logistical challenges that families may face. Future work focused on patient-centered care and shared decision-making is vital to improve patient care and outcomes.

This study has several limitations. First, it involved a limited sample from a single academic center for interviews. This means that the findings may not be nationally representative about experiences related to UPJO surgical decision making. Second, while we utilized purposive sampling to obtain a diverse perspective from families with a wide range of backgrounds and treatment, we were only able to conduct interviews in English and Spanish leading to potential selection bias. Despite these limitations, we believe that this study offers new insights into how parents experience both the diagnosis and decisions about treatment for UPO and identifies potential opportunities to enhance parental participation in shared decision-making, areas that have not previously been studied.

#### 4.2. Innovation

The use of parent-centered qualitative interviews, coupled with purposive sampling across multiple demographic groups, offers a novel approach to address quantitative findings of variability in the care of infants with a surgical diagnosis, such as UPJO [5,20]. While qualitative methods are not new, their application in surgery in general and pediatric urology specifically has been limited. Integration of qualitative research has been described as a way to augment limitations of quantitative studies alone. Additionally, direct engagement of parent stakeholders offers the opportunity to directly influence the effect of patient decision aids in pediatric surgery by addressing needs identified by parents and thereby allowing for tailoring of decision aids and other interventions to provide patient and family-centered treatment. By purposively engaging rural and non-English speaking families, this study also offers the opportunity to better understand cultural and demographic differences in parent-identified gaps in current decision-making processes, an area not previously well explored in pediatric urological research [21]. This focus on patient/parent decision-making and development of tools to support parental engagement in decision-making is relatively novel, with only two decision aids developed in this space, neither of which has been formally tested [22,23]. Furthermore, as identified by our study, the concerns facing parents and families in the pediatric setting may differ from those identified in adult patients. As a result, the data gleaned from this study offers the potential to improve health outcomes for these children by acknowledging and addressing parent-identified concerns and barriers to meaningful engagement in care, thereby offering a family-centered approach to designing and implementing future research in pediatric surgical populations.

#### 4.3. Conclusion

These findings suggest the need to increase parent education and understanding, and the need to enhance psychosocial support for more meaningful parental engagement in the surgical decision-making process. In this study, parents identified common challenges associated with the uncertainty and unpredictability of their child's medical diagnosis and surgical decision-making. Parents also highlighted the common logistical challenges that are encountered as part of following through on the treatment plan for their child. Finally, parents highlighted the often-overlooked psychosocial factors that contribute to their experience related to their child's diagnosis that may impact their decision-making. We recommend development of a patient decision aid that actively involves the perspective of parents, as outlined in the findings from this study, that will help to reflect family values, preferences, and needs to support optimal outcomes for patients with UPJO and their families.

I confirm all patient/personal identifiers have been removed or disguised so the patients/persons described are not identifiable and cannot be identified through the details of the story.

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### CRedit authorship contribution statement

**Cindy L. Buchanan:** Data curation, Formal analysis, Writing – original draft. **Megan A. Morris:** Methodology, Data curation, Supervision, Writing – review & editing. **Daniel Matlock:** Validation, Writing – review & editing. **Allison Kempe:** Conceptualization, Supervision, Writing – review & editing. **Vijaya M. Vemulakonda:** Conceptualization, Formal analysis, Funding acquisition, Validation, Writing – review & editing.

### Declaration of Competing Interest

None.

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