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Parent Experience of Communication about Children's Surgery: A Qualitative Analysis

Lauren E Claus, BA*; Anne R Links, MS, MHS*; Janine Amos, DO*; Heather DiCarlo, MD†; Eric Jelin, MD‡; Rahul Koka, MD, MPH§; Mary Catherine Beach, MD, MPH¶ Emily F. Boss, MD, MPH*

Abstract

Introduction: Parent experience is a core component of the quality of pediatric care and an increasingly common focus of quality improvement initiatives. However, the parent experience of communication in the pediatric surgical setting remains unexplored. **Methods:** We conducted semi-structured interviews with 20 parents of children undergoing surgery. Interviews were analyzed using directed qualitative content analysis. **Results:** Content analysis revealed 3 overarching themes. The theme of "*provider–parent communication*" included interpersonal behaviors and communication-originating skills of the surgeon. Parents valued surgeons incorporating multimodal information-sharing techniques, recognizing children's psychological needs, providing reassurance, engaging in teamwork, and including parents. The theme of "*parental emotional experiences*" included domains of parent worry, intimidation, offense, self-doubt, mistrust, and strength surrounding their child's surgery. Parents felt simultaneously responsible for their child's welfare and for understanding medical information. The theme of "*process improvement*" included preparation for surgery, efficiency, managing delays, anesthesia induction, emergence from anesthesia, privacy, and preparation for recovery. **Conclusions:** Themes identified through these parental narratives and proposed solutions inform quality improvement efforts related to surgeon communication strategies and facilitate family-centered surgical care for children. Parents often provided solutions after they described concerns, which attests to the utility of parent perspectives. (*Pediatr Qual Saf 2021;6:e403; doi: 10.1097/pq9.000000000000000000403; Published online May 19, 2021.*)

INTRODUCTION

Parent experience is increasingly recognized as a fundamental component of the quality of pediatric health care.¹ As such, contemporary quality improvement initiatives commonly incorporate family perspectives.² Through improving their communication with families, providers can impact patient and family experiences of care and decision-making.³ Such



From the *Department of Otolaryngology, Johns Hopkins University School of Medicine, Baltimore, Md.; †Department of Urology, Johns Hopkins University School of Medicine, Baltimore, Md.; ‡Department of Surgery, Johns Hopkins University School of Medicine, Baltimore, Md.; §Department of Anesthesiology, Johns Hopkins University School of Medicine, Baltimore, Md.; ¶Department of Internal Medicine, Johns Hopkins University School of Medicine, Baltimore, Md.

*Corresponding author. Address: Emily Boss, 601 N Caroline St, Baltimore, MD 21205

PH: 410 955 9772; Fax: 410 955 0035 Email: erudnic2@jhmi.edu

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intermediary outcomes are, in turn, associated
with greater satisfaction, improved adherence to treatment, and more favorable
health outcomes.⁴⁻⁶

In consultations for elective surgery, families often have only brief opportunities to learn about treatment options and consider undergoing surgery or pursuing other treatment strategies.^{7,8} Moreover, the perioperative spectrum of care includes additional anxiety-provoking elements for

families, including risks associated with procedural interventions and anesthesia.^{9,10} Patient-centered and empathic communication is associated with less perioperative anxiety.¹¹ However, studies that have examined communication between surgeons and adult patients have identified a pervasive lack of empathic communication and informed decision-making.^{12,13} Furthermore, studies have shown that parents prioritize elements of surgical intervention, which are often not highlighted during presurgical counseling, including anesthesia risks and postoperative diet.^{14,15} Parents' overall communication needs and preferences regarding surgical care for their children remain relatively unexplored.

In this study, we elicit parent narratives of their communication experiences across the spectrum of elective surgical care for their children, including the incorporation of parents' emotional responses. Through qualitative analysis, we aim to understand families' experiences, promote relationship-centered surgical care for children, and inform quality improvement efforts in pediatric surgery.

METHODS

The Johns Hopkins University Institutional Review Board approved this study (IRB47806). Parents were eligible to participate if their child had undergone elective surgery at Johns Hopkins Hospital 2–12 weeks before the interview. This timeframe was selected to include parents' long-term experiences with postoperative recovery but to avoid situations in which parents forgot specific details about perioperative experiences. Parents were recruited during postoperative telephone follow-up calls and medical appointments at Johns Hopkins Hospital. If the potential participants agreed to participate in an interview about their experiences communicating with surgical care providers, the interviewer obtained verbal informed consent over the telephone or in-person before beginning the interview.

Data Collection

We conducted semi-structured interviews between June and August 2018. A co-investigator versed in qualitative and narrative methods (LC) led the interviews. Interviews followed an iterative question guide, which was developed based on prior research of parental perspectives of sleep-disordered breathing in children.^{13,22}

The semi-structured interview guide included demographic questions and questions about parents' experiences communicating with health care providers surrounding their child's surgery. These questions included parents' overall experience ("Before your child's surgery, what were your main concerns?"), communication ("How would you ideally want [the surgical care provider] to speak with you about surgery?"), provider/parent relationship ("What made you trust/not trust your surgical care provider?"), and parents' emotional response ("How did you feel about your child's surgery?"). Interviews were conducted over the telephone or in-person, based on parent choice and availability. The team concluded interviews when they reached thematic saturation and could reasonably assume that further interviews would add information similar to that already collected.

Analysis

Interviews were audio recorded and transcribed. Transcribed interviews were analyzed using qualitative content analysis. Our team's prior research in patient–provider communication was used to template key concepts and potential surgeon–parent communication themes before coding.⁸ Building upon this foundation, content analysis identified emerging themes in parental experiences of communication.

In conducting thematic content analysis, study team members familiarized themselves with the transcripts and identified emerging domains within each partially preconceived theme. A detailed codebook was developed based on the prevalence of major themes and subdomains within the transcripts and approved by all study team members. Using the defined themes within this codebook, a team member (LC) systematically coded each transcript independently. An additional team member (JA) coded 25% (n = 5) of the transcripts. Inter-coder agreement was calculated for each identified theme via kappa analysis and considered adequate at a threshold of >80% observed agreement. Study team members met to discuss discrepancies when agreement was inadequate and reached consensus on how the responses should be coded.

RESULTS

Participants

Parents of 23 children who had undergone surgery were approached for participation in this study, and 20 parents agreed to participate, yielding a response rate of 87%. Interviews lasted between 15 minutes and 1 hour, with a mean of 34.75 minutes and a median of 27.5 minutes. Interview lengths were dependent on the extent of information parents wished to share; we set no prior minimum or maximum timeframe. We conducted 5% (n = 1) of interviews in-person due to parental preference and availability.

Surgeries were performed by 13 surgeons of different pediatric specialties: general surgery (n = 7), otolaryngology (n = 5), plastic surgery (n = 3), urology (n = 3), gastroenterology (n = 1), and orthopedic surgery (n = 1). Ten (50%) of the children had undergone at least one prior surgery at Johns Hopkins Hospital before the surgery discussed in the interview. Parents interviewed were mostly mothers (n = 18, 90%). Eleven parents (55%) were white, 7 (35%) were African American, and 2 (10%) were identified with other ethnicities. A majority of children were boys (n = 13, 65%) with a mean age of 10.9 (SD = 4.9). Participant characteristics are shown in Table 1.

Thematic analysis

Qualitative content analysis yielded 3 overarching themes of parent experience: 1) surgeon communication; 2) parent emotional experience of communication; and 3) process improvement (Tables 2 and 3). Parents also provided constructive recommendations as a reflection of their experiences (Table 4 and Fig. 1). Data saturation was reached after no new themes emerged from analysis. Initial interrater agreement was 71.3% for provider-parent communication, 69.2% for parent experience, and 85% for process improvement. The study team discussed and resolved all discrepancies that yielded inadequate agreement, including the discrepancies that impacted the inter-rater agreement of provider-parent communication and parent experience. The final agreement for all themes met consensus.

Surgeon Communication

Parents described how providers interacted and communicated, including identification of providers' interpersonal

Table 1.	Participant	Characteristics ((N = 20)	

Characteristics	n (%)
Parent gender	
Male	2 (10)
Female	18 (90)
Child gender	
Male	13 (65)
Female	7 (35)
Parent race/ethnicity White	11 (EE)
African American	11 (55)
Asian	7 (35) 1 (5)
Other	1 (5)
Child's current age, mean (SD)	10.85 (4.8711)
Familiarity with surgery	10.00 (1.07 11)
Repeat surgery patient at Hopkins	10 (50)
First-time surgery patient at Hopkins	10 (50)
Days after surgery interviewed, mean (SD)	25.2 (23.46)
Specialty of surgeon and procedure*	
Otolaryngology (cochlear implant insertion, meato-	5 (25)
plasty, myringotomy, tonsillectomy, tympanostomy	
tube insertion)	
Gastrointestinal (esophagogastroduodenoscopy)	1 (5)
General (burn scar laser treatment, catheter removal,	7 (35)
hernia repair, median arcuate ligament release,	
draining of perirectal abscess)	
Plastics (cleft palate repair, nevus removal, skin lesion excision)	3 (15)
Orthopedics (right forearm closure)	1 (5)
Urology (cystoscopy, hypospadias repair, stomal	3 (15)
endoscopy)	- (10)

"3 burn scar laser treatments performed (15%). All other surgeries listed performed only once (5%).

characteristics. Most parents reflected positively on provider characteristics, reporting that they were "kind" or "pleasant" and provided reassurance or normalization. Parents appreciated providers with a calm or reassuring affect ("the doctor was really calm and ... making her feel good and ... making her daddy, 'cause he was freakin' out too"). However, there were some discrepancies in parental preferences for provider behavior. While some parents appreciated friendly providers ("bubbly ... in a happy place"), others appreciated direct providers ("more succinct ... I don't like a lot of fluff"). Parents appreciated being included in the decision-making process, on both an individual ("even if he doesn't agree with me he will hear what I have to say") and group ("they make us feel a part of the team") level. They also appreciated witnessing teamwork among health professionals. However, some parents reported feeling uncomfortable when providers initially encouraged parents' participation and then retracted their support:

"So the second time I tried, I didn't get it, and Dr. X said yeah you're not ready. And he literally turned on his heels and walked out of the office. And it made me feel terrible as a parent, it made me feel like a failure."

Parents often wished that surgeons provided more insight and psychological preparation about the physical consequences of surgeries for their child, and recognized their child's needs more thoroughly. Parents recalled their feelings of inadequacy when discussing the reasons for and consequences of surgery with their upset children ("she thought she looked like a monster ... the way we talk with her ... didn't make her feel any different"). As one parent reflected:

"Honestly one of my concerns was his kind of his mental wellbeing through all of this he asked me why did you make me do this, and I did say you want to be a daddy someday ... that is something that parents should be coached to say."

In addition to suggesting that surgeons provide detailed guidance on how parents could communicate expectations and outcomes of surgery to their children, parents addressed standard elements of communication such as language use, information-sharing, and availability. Parents stated that when surgeons shared clear and concise information, their anxiety was reduced ("*He explains it to me in a way I can understand, and that anxiety goes away*"). They also

Table 2. Representative Quotations about Provider-Parent Communication (N = 20)

Theme	Representative Quotations		
Interpersonal characteristics (n = 19)	"He had us at such ease that if he would've said, 'If we drop [him] on his head, it will fix him,' I'd seriously think about it He presented himself as such a calm person that was under such control of the situation." "I'm always like the champion and the cheerleader and I'm like 'yay we're going to do it,' and inside I'm like dying."		
Reassurance for parents $(n = 10)$	"She relieves anxiety that's what they deal with every day. They know how parents are feeling and what to do to get them to feel better."		
Recognition of child's psy- chosocial needs (n = 9)	"He said things like it's ugly, it's disgusting, it looks gross you just think about boys and his penis and the self-es- teem and the mindset. I would have appreciated them taking the lead on that: like these are some things that he may be thinking or feeling, these are some things that we could maybe say if that happens."		
Professional teamwork $(n = 8)$	"She works well with others she's going to get the chemistry from the nephrology side of the house, the timing from the anesthesia side of the house That's also peace of mind."		
Multimodal information- sharing (n = 7)	"What's most helpful are the actual x-rays and photographs that we used each time to make comparisons." "It was better with the pictures because then I'd see what my daughter's ear was gonna look like if I didn't know that going in, I would have panicked."		
Inclusion of family $(n = 4)$	"He's always including me. And even if he doesn't agree with me he will hear what I have to say about it." "I think that basically he didn't want me to do it. I feel like he was even annoyed at the idea of teaching me how."		
Availability (n = 3)	"She has sent me emails at two a.m. that said, 'I woke up and I was thinking about [Name] and how I could do X, Y, Z.' She treats it like this is her body of work. What that does for my blood pressure and my wellbeing, I can't explain."		

n, number of participants whose interview included this theme.

Theme	Representative Quotations		
Worried (n = 20)	"This is one of the most stressful days a parent will ever have. Handing your child over for surgery, no one is at their best. Everyone is at their kind of weakest moment. You play that lottery with your most precious commodity, your child."		
Responsible for child's welfare	"I always say parents are forced to be the case manager."		
(n = 15)	"Trying to be like old buddy, old pal, just to make her feel calm once it was all over I can go back to being a mom."		
Responsible for understanding information $(n = 11)$	"Oh my gosh I would be scrambling to take notes on everything that they said So it was hard for me to multi- task. I always brought someone with me because I couldn't manage my child's care and listen at the same time.		
Strength (n = 8)	"As parents you have to be stronger and you can't show that to them. Because it's many a nights that me and her dad have held each other while we cried."		
Dismissed ($n = 6$)	"I felt really unheard and when I was in the car and we were leaving, I cried."		
Intimidated $(n = 5)$	"The surgeon's gone to medical school. They have this prestigious career filled with experience. Parents get intimated by their education, by their title." "You know, doctors are exalted, right?"		
Offended $(n = 4)$	"He did show us a picture of that how [he] is straight and he did say, 'what sorority girls won't like that.' That off- handed sexual joke about my son wasn't appropriate."		
Overwhelmed $(n = 4)$	"When you're a parent it's sensory overload when you're trying to help your kid and you have these really import ant questions that to the doctor are pretty standard I don't do this every day and this is my baby."		
Self-doubt (n = 4)	"We were like, 'What have we done to her?' She was in pain, she was crying. We were just always second guessing it."		
Mistrust (n = 4)	"I've gotten to the point now that I don't even trust that. I just don't even know if they're saying that because it's hubris."		

Table 3. Representative Quotations about Parent Emotional Experience of Communication (N = 20)

sometimes described the utility of clear and thorough directives ("*They would say 'Hey this is our goal, this is what we're working towards'* ... and we understood as parents"). They emphasized that multimodal information-sharing, which included X-rays, photographs, and drawings, was especially useful. Indeed, when asked how surgeons might improve communication, many parents suggested that providers use visuals ("*I just wanted to see what my son's ears look like now*"). Parents also discussed provider availability and appreciated when they were able to easily query or access providers from outside the hospital.

Parent Emotional Experience of Communication

Parents elaborated specifically on their own negative experiences and emotional reactions to their child undergoing surgery. Parents were typically worried and equated the surgical experience with stress, describing it as expected ("normal anxiousness") or pronounced, with one parent describing surgery as "one of the most stressful days a parent will ever have." Despite accounts from parents stating that thorough preoperative information from surgeons helped dispel stress, others indicated that communication could only partially allay their worries, as providers could not fully empathize. Some parents took sole responsibility for their emotional reactions ("I think it was more just me, you know") or expressed gratitude for surgeons' empathy ("They were very empathetic ... They understood our needs"). However, others held surgeons accountable, desiring greater empathy from surgeons:

"I just wish that surgeons understand that the emotional toll that it takes on families ... They don't truly understand that aspect, so they just need to be mindful of even if a family like us that's went through so many surgeries, it's never easy." Parents also described off-putting interactions with surgeons. They often felt intimidated by surgeons' expertise and education and reported feeling concerns that their questions were "*silly*" or "*not smart enough*." Parents acknowledged responsibility for understanding information relayed by the provider and reported feeling overwhelmed by the amount of medical information given during conversations. They often relied on note-taking to understand their child's disease.

Parents also reported feeling offended or dismissed when providers did not believe or acknowledge their concerns or their child's concerns, or abruptly ended conversations. These feelings often persisted over time, accumulating into overall mistrust (*"I felt really unheard... after that experience I've always had that guarded feeling every time I go to a clinic visit"*). Parents sometimes discussed self-doubt about their decision to pursue surgery. However, they described keeping such feelings to themselves and needing to act in additional roles such as "psychologist," "case manager," "advocate," or "friend," which conflicted with their roles as parents but supported their perception of themselves as being responsible for their child's welfare. Similarly, they discussed the need to show strength to reassure their child:

"I need that kind of little bit of emotional support to help me stay strong ... I'm always like the champion and the cheerleader and I'm like 'yay we're going to do it,' and inside I'm like dying."

Process Improvement

Parents identified logistical factors of the perioperative process that could be addressed to improve the experience and reduce anxiety (Table 4). Parents called the timeline

Theme	Parent's Concern	Parent's Solution
Recognition of Child's Psychosocial Needs	"It rekindles all of those memories of the night that the incident happened and the person who caused it. It steers a little bit her emo- tions back up."	"From the hospital staff and the doctors, they tried to be very upbeat and relaxed and cheerful, and I think that is incredibly helpful."
Information-sharing	"I just wanted to see what my son's ears look like now, you know?"	"I wanted a diagram of what the PE tube would actually look like."
Intimidated	"But it can feel intimidating because you're there."	"What advice I would give is don't be intimidated. Don't be intimidated by their credentials, don't be intimidated if you feel that your questions might not be smart enough."
Offended	"And the doctor sat us down He goes, 'I think your son's making it all up.'"	"That phrase was the downside. It would have been much better just saying, 'We didn't visibly see anything, but we're waiting for results from biopsies to give a more clear picture.'"
Dismissed	"And he literally turned on his heels and walked out of the office. And it made me feel like a failure."	"If I were to ask for anything, just more peaceful patience. And not feeling like we were just a cog in the wheel When they come into the room, to sit down, to maybe not do like the speed talking Maybe not leave until 'hey, do you have any other questions?'"
Strength	"I'm always the champion and the cheerleader and I'm like yay we're going to do it and inside I'm like dying."	"So the little bit of support from the doctors and the nurses, the moral support, it really helps in situations like this."
Preparation for surgery (day of)	"They don't call you until very late in the day before to let you know what time to arrive, which is a little nerve-racking for me."	"I was just surprised at how late it was in the day that they called. I would've preferred that it had been a little earlier."
Anesthesia	"I really didn't like the way that they said, 'We're going to give you a new pacifier' He had no clue what that meant then."	"I would know which language would be most reassuring for him and the least scary. I needed those three seconds to just explain to him."

of the process "frustrating" and described difficulties reaching the office for scheduling. They discussed preparation for the day of surgery, finding it "nerve-wracking" to learn the start time of surgery only the day before the procedure. Although some parents experienced "anxiety" (even a "panic attack") because of perioperative waiting, one parent suggested that parents' anxiety about waiting reflects their unfamiliarity with the pediatric surgical setting: "If you aren't a frequent flyer ... it's hard to have the perspective ... Your child going later ... actually is a good thing because it means you're not the sickest kid." In addition to discussing preparation for surgery, some parents also felt they were unprepared for recovery, including managing their child's reaction post-surgery ("I guess the social-emotional needs—I would have appreciated if that was addressed as much as the physical needs").

Parents provided different views about parental presence during anesthesia administration and emergence. At Johns Hopkins Hospital, a single parent is allowed to accompany each pediatric surgical patient to the operating room and to remain present during the induction of anesthesia, unless exceptional circumstances—such as the Coronavirus Disease 2019 pandemic—preclude parental presence. While some parents valued this experience and reported that providers had prepared them for it, others reported increased stress, and 2 parents called this experience "*traumatic*." One parent wished she could have better prepared her son: "*they just slapped it on his face.*"

Similarly, parents appreciated the opportunity to witness their child emerge from anesthesia in the Post-Anesthesia Care Unit. Parents became "*distraught*" if they missed their child awakening, even just by seconds ("*by the time I got to him, my son was screaming in a stranger's arms*"). Parents most often discussed their desire to be present with their child throughout an efficient perioperative process, especially during the onset and awakening from anesthesia ("*I think my biggest concern was being able to be with him ... until he falls asleep ... right away when he wakes up*").

Parents also found the hospital setting lacked ideal privacy. They reported a strong desire to share their experiences only with their family and not with other "*parents that are watching and experiencing the same operating room emotions.*" They identified the waiting room and the Post-Anesthesia Care Unit as especially public spaces where providers could improve processes to check in with families about needs for privacy or close curtains and lower voices before delivering news.

Parents' suggestions for process improvement related to logistic concerns (scheduling) and emotional support (parent/child reactions to anesthesia). Furthermore, the overarching themes of both communication and parental experiences were integrated into discussion of improving the perioperative process, as better communication may ameliorate postoperative difficulties (Fig. 1).

DISCUSSION

This study builds on previous research evaluating parental experiences by investigating parent experiences of provider communication during the perioperative process of elective pediatric surgery. This is the first study to qualitatively report parents' emotional reactions, values and preferences related to surgeon-family communication in the pediatric perioperative setting. Parents discussed themes related to provider-parent communication, their experiences, and ways to improve the perioperative process. Parents often supplemented specific concerns with concrete solutions, underscoring the importance of using

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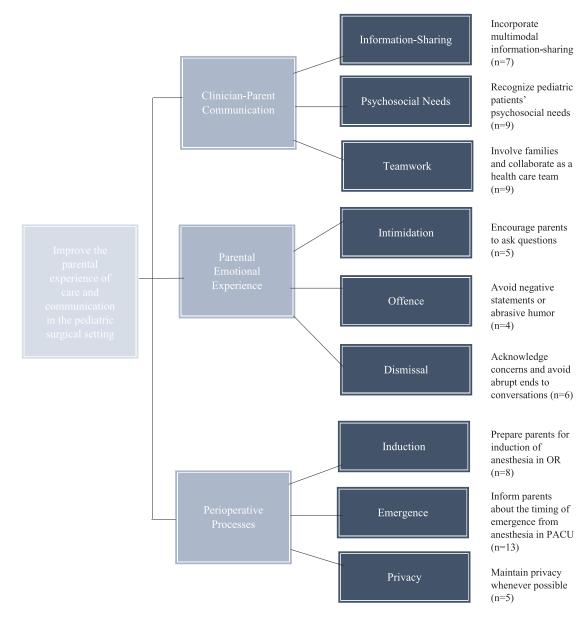


Fig. 1. Key Driver Diagram-Model for Improving the Parental Experience of Care and Communication in the Pediatric Surgical Setting

family-centered perspectives and outcomes to improve quality of care.

Parents valued multimodal information-sharing. This finding provides insight into optimal methods of information-sharing and decision-making. Parents highly value effective explanations of procedures.¹⁰ As such, surgeons could improve information-sharing and families' overall experiences by incorporating pictures or diagrams into educational conversations about the care of patients.¹⁵ Decision support tools have been introduced throughout healthcare and surgical environments.¹⁶ Tools help parents visually understand risks, benefits, and treatment alternatives for procedures, including tonsillectomy and appendectomy.¹⁷ Use of these tools in surgical practice, even as an adjunct to discharge materials or after clinic visit summaries, may provide the information support that is lacking.

There is a gap surrounding research about how surgeon behavior influences parent feelings of intimidation and self-worth. Many studies have explored how health care workers such as nurses and medical students feel intimidated in perioperative settings, but these studies have not addressed patient/parent intimidation due to surgeon communication.^{18–20} Studies have focused on identifying "missed opportunities" for surgeons to address patients' negative emotions, showing that providers may respond with inadequate acknowledgment, inappropriate humor, or denial instead of recognizing parents' emotions.^{21,13} In this study, parents described how they felt intimidated, dismissed, or offended by surgeons, citing instances such as a surgeon joking about a patient or leaving a room abruptly without proper explanation. Surgeons could improve communication with families by modifying nonverbal behavior and emotional cues. We previously found that surgeons use complex medical language, especially when they perceive parents to be more engaged in the decision-making process, regardless of parents' actual level of understanding.²² There is an opportunity for surgeons to universally modify their language by including medical explanations, discussion of treatment alternatives, emotional cues, and nonverbal behavior during discussions with families.

Parents emphasized stress related to anesthesia. It is well known that parents and children experience anxiety about anesthesia. Parents may be more anxious about the anesthesia required for adenotonsillectomy than about the surgery itself, and surgeons may underestimate parents' concern about anesthesia.8,10,23,24 Significant debate surrounds the topic of parental presence during anesthesia induction and emergence, but no differences have been identified in anxiety when comparing parents present or absent during induction.25-27 Furthermore, parental involvement in anesthesia induction and emergence could compromise patient and family safety.²⁸ In the Post-Anesthesia Care Unit, it is important to ensure stable postoperative recovery is established before families enter the room, although many parents in our study believed it was vital for them to be present as their child emerged from anesthesia. Health care providers can counsel parents about issues with emergence and instill accurate expectations surrounding anesthesia to reduce the anxiety that families experience. Our study suggests that a degree of anxiety should be expected among families, but specific interventions involving more effective communication about anesthesia administration and emergence may decrease the perioperative anxiety that parents and children experience. This research may help inform quality improvement efforts that focus on parental expectations in the pediatric surgical setting, including the development of a process map that is publicly available and disseminated to parents pre-operatively.

This project represented a first inquiry into parents' personal values and preferences related to communication about surgery in children. There were some limitations to our study. The sample had a degree of heterogeneity because 5% (n = 1) of the interviews were conducted in-person, while the rest of the interviews were conducted over the phone. Although data were partially double-coded to confirm analytic validity, it is possible that results are impacted by coder bias because qualitative analysis involves a degree of subjectivity. We also expect that parents may have different values and preferences. Some perspectives may have been influenced more than anticipated by the surgical discipline or complexity of the child's procedure. Furthermore, our study was conducted at a single tertiary institution, and as such, results may not apply to all pediatric surgical settings. Given the anonymity of quantitative parent experience measurements at our tertiary care institution, we were unable to correlate our results with surgeons' family experience scores. This is an important area for future research, given our previous finding that patient satisfaction scores are highest for the provider domain in pediatric surgical care.²⁹

CONCLUDING SUMMARY

We present parent experiences of communication in the pediatric perioperative setting. Despite positive interpersonal experiences with providers, parents characterize their overall experiences as negative due to their emotional experiences. Parents often provided solutions after they described concerns, suggesting the utility of eliciting parent perspectives. Providers can incorporate these parent perspectives into quality improvement efforts and more effectively engage in decision-making by understanding the intensity of parents' emotional experiences related to pediatric surgery.

DISCLOSURE

The authors have no financial relationships relevant to this article to disclose.

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