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Long-term pain and recovery after major pediatric surgery: A qualitative study with teens, parents, and perioperative care providers

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Abstract

Research developing targeted treatment focused on coping with children's long-term pain after surgery is needed due to the high prevalence of chronic pain after surgery. This qualitative study aimed to 1) understand the child's and family's experiences of pain over the course of their surgical experience, and 2) gather stakeholder input regarding potential barriers and facilitators of perioperative intervention delivery. Fifteen children ages 10–18 years who underwent recent major surgery, their primary caregivers, and 17 perioperative healthcare providers were interviewed. Interviews were coded using semantic thematic analysis. The perioperative period presented emotional challenges for families. Families felt unprepared for surgery and pain. Recovery and regaining physical functioning at home was challenging. Families struggled to return to valued activities. Families reported interest in a perioperative psychosocial intervention. Providers endorsed that families would benefit from enhanced coping skills. They emphasized that families would benefit from more detailed preparatory information. Providers suggested that flexible intervention delivery at home would be ideal. Research developing interventions addressing pain and anxiety in children undergoing major surgery is critically needed. The findings of the present study can inform intervention development with the aim of improving both short and long-term recovery in children undergoing major surgery.

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INTRODUCTION

Approximately one million children undergo inpatient surgery in the U.S. each year⁸ and many experience significant pain and distress in the hospital as well as at home after surgery. In the weeks leading up to surgery, attention is placed on medical optimization and planning for surgery, anesthesia, and hospitalization. Over recent years, children are discharged increasingly early in the recovery process, with discharge criteria usually including resumption of an enteral diet, ability to take oral pain medications, and mobilization out of bed. Therefore, when children return home from the hospital, they often face weeks of continued healing and recovery. During this time, many children experience significant postsurgical pain which can impact their health outcomes²⁰. Recent studies indicate that about 20% of children report persistent postsurgical pain at 6 to 12 months after major surgery,^{18,21} which is associated with functional disability and decreased quality of life²¹. However, limited research has examined children's and families' experiences with postsurgical pain at home once they leave the hospital.

Psychosocial risk factors for chronic postsurgical pain have been studied in children and their families. For example, pre-surgery levels of anxiety and catastrophizing about pain in children and their parents predicts pain intensity months after surgery^{6,21}, suggesting that interventions targeting psychosocial risk factors may improve children's pain and health outcomes after major surgeries. A recent systematic review identified psychosocial interventions targeting pain at home as an important gap in existing literature, which predominantly includes in-hospital short-term interventions intended to address acute recovery⁷. These few studies have investigated preoperative preparation for the acute surgical experience, and delivery of psychological interventions (e.g. distraction and guided imagery) during the immediate perioperative period in the hospital^{4,7,11,12}, finding equivocal effects on short-term pain intensity, and no effects on pain outcomes beyond hospital discharge^{4,7,12}. Research developing targeted biopsychosocial approaches focused on preventing and coping with children's long-term pain and recovery at home after surgery is therefore critically needed.

While existing research has identified several important risk factors for chronic postsurgical pain in children, our understanding of children's experience of pain at home remains limited, impacting our ability to successfully develop interventions to improve long-term outcomes. In order to bridge these gaps, qualitative research can provide rich data to better understand patient and family experiences with persistent postsurgical pain, to elucidate the course of pain, and to recognize potential novel factors impacting recovery at home after surgery. Such data may be used to inform development of a perioperative psychosocial intervention program. Qualitative research can inform researchers and clinicians on patient, family, and providers' beliefs and attitudes, assessing receptiveness, and recognizing potential barriers and facilitators to a psychosocial intervention²⁷. Furthermore, qualitative research can inform development of measures assessing domains relevant to the context of surgery to evaluate intervention outcomes.

Therefore, we conducted a qualitative study to understand long-term pain and recovery at home after major surgery utilizing perspectives of three important stakeholder groups,

children, parents, and health care providers. Our first aim was to understand the child's and parent's experiences of pain over the course of their surgical experience (before surgery, perioperative period, post-surgery period). Our second aim was to gather stakeholder input from children who underwent surgery, their parents, and perioperative providers regarding potential barriers and facilitators of intervention delivery in the perioperative period. To ensure high quality in reporting our methods and results, we complied with the Standards for Reporting Qualitative Research¹⁵.

METHODS

Participants and setting

Child and parent participants—Participants included a convenience sample of 15 children ages 10–18 years who underwent recent major surgery, and their 15 primary caregivers, who had participated in a larger longitudinal study of pain and health-related quality of life. All participants were recruited from a university-affiliated children's hospital in the Northwestern region of the United States. Exclusion criteria included non-English speaking children and children who had developmental delays or a severe medical comorbidity. Families were eligible for the qualitative study if the child had undergone surgery 3–12 months prior. Participant characteristics are presented in Table 1.

Provider participants—The health care provider group was comprised of a representative sample of 17 perioperative healthcare providers (13 female, 4 male, mean age = 39.2 years, range 26 – 62) including two surgeons, six perioperative nurse practitioners (pre-anesthesia clinic, pain medicine team, and surgery clinic), two physical therapists, two child life specialists and five inpatient surgical nurses practicing at the same children's hospital with an average of 14.9 years (range 3 – 36) of professional experience. Healthcare providers were selected based on inclusion of a variety of provider roles and expertise in caring for children undergoing surgery.

Study Design and Procedures

Recruitment—The study was approved by the university's Institutional Review Board. A study research assistant contacted eligible families by phone between August and November 2015 to describe the study and invite participation. Those interested in participation completed verbal consent and assent and were scheduled for an in-person or telephone interview. Sixteen families were approached for potential participation, of which one family declined due to lack of time. Parents and children completed the interviews independently to avoid influencing the other's responses. Families were compensated for their participation with gift cards.

Provider participation was invited through communication via the heads of the provider groups, followed by direct communication by a study research assistant. Participants completed verbal consent before completing the interview process.

Semi-structured interviews were conducted individually by 4 trained interviewers, which included 3 authors. Interviews were completed by phone or in person in a private conference room at Seattle Children's Hospital between August and December 2015. Where a

relationship existed between the interviewer and the participant, a second interviewer facilitated the discussion. The interviewers were trained by the senior author in semi-structured interview techniques to elicit information through non leading questions, and were given example questions developed to elicit information addressing the study aims. Families and providers were asked open-ended questions in six domains including perioperative challenges, emotional experience, long-term recovery, post-operative outcomes, interest in perioperative psychosocial intervention, and potential barriers and facilitators to participating in an intervention. Within each of the categories, families and providers were asked two or more questions to elicit information (see Table 2). Interviews were audio recorded, and field notes were taken. Initial analysis of interview data occurred concurrently with data collection, which informed addition of interview questions based on evolving study findings.

Thematic analysis

Qualitative interviews were coded using inductive methodology of semantic thematic analysis, which entails deriving all codes directly from the data using a “bottom-up” approach. Thus, no pre-identified theoretical framework or codebook was used to generate initial codes. Rather, consistent with our aims, we sought to summarize explicit themes from the interviews. Coding followed six phases of thematic analysis methodology described by Braun and Clarke (2006)², with strategies to enhance qualitative rigor applied systematically throughout^{28,29}. Parent-child interviews and provider interviews were analyzed separately to ensure that differences in family and provider perspectives were preserved throughout the coding process.

Interviews were deidentified and assigned a participant number, with corresponding numbers assigned to members of the same family (i.e. parent and child). Interviews were transcribed and imported into NVivo software (version 10; QSR International Pty Ltd, 2012). Coding was conducted by 6 members of the author team. Two members of the coding team had previous experience with coding qualitative data. Other members of the coding team underwent training with experienced coders in our research laboratory. To identify the codes, categories, and then themes, coders first read the full transcripts to gain familiarity with interview content. Two primary coders identified meaningful units of text and applied initial codes based on semantic similarity. Complete transcripts and initial coding were reviewed and refined by two secondary coders. The study team met regularly with primary and secondary coders to organize codes into analytical categories. Coding was then reviewed for differences and commonalities both within and across code categories, refined, and given provisional definitions. Categories were then synthesized into explicit themes addressing the study aims, with consensus obtained at each stage.

In order to increase trustworthiness of the findings, we sought to strengthen dependability, confirmability, and credibility²⁹. To ensure dependability, a detailed analysis plan regarding the stages of analysis was created before we conducted the interviews, drawing from peer reviewed qualitative research methodology² and agreed by all study team members. This was followed throughout the analysis. In order to increase confirmability of the analysis and results, the team was comprised of individuals with expertise in pediatric psychology, adult

psychology, and perioperative medicine. This triangulation of expertise within the team provided different perspectives and interpretations to expand understanding of the interviews²⁹. To ensure reflexivity, coding meetings included time for critical discussion of individual perspectives from all members of the study team, which was enhanced by the multidisciplinary nature of coding groups²⁸. In order to increase credibility, two of the study team members returned after provisional coding and read through the transcripts once more with the coding scheme to ensure that it reflected the data, and identified representative quotes^{3,29}.

RESULTS

Child and parent interviews

From the child and parent interviews, five themes were identified including, 1) the perioperative period presented emotional challenges for families, 2) families felt unprepared for surgery and postsurgical pain, 3) recovery and regaining physical functioning at home was challenging, 4) families struggled to return to valued activities, and 5) families reported interest in a perioperative psychosocial intervention.

The perioperative period presented emotional challenges for families—Prior to surgery, children were afraid of experiencing pain, and of the surgery itself. They were concerned about regaining function, and worried about potential complications including paralysis, infection, and that surgery would not be as successful as hoped.

“I was petrified of the thought of surgery; it scared me to my bones. I didn’t want to get paralyzed.” (Child 8)

“I was more just worried about the pain... worrying about the pain was worse than the actual pain.” (Child 4)

Children experienced anxiety on the day of surgery. They reported specific fears related to surgery including the sight of needles and equipment, and waking up during surgery. In the hospital, children struggled with unanticipated vulnerability related to being physically exposed and requiring assistance with toileting and bathing, which continued during the early recovery period at home.

In response to perioperative challenges, children employed maladaptive coping strategies, including avoidance and repression, as well as adaptive coping strategies, including acceptance, positive thinking, distraction, and seeking support from family and friends.

The surgery experience also presented unique stressors for parents who reported worry about complications prior to surgery. Parents struggled to see their child in pain and felt guilty for putting their child through surgery.

“You cannot imagine as a parent what it is like to see your child in so much pain and to know that you made the decision to put them there... you ultimately made the decision for them to be in so much pain and that is hard.” (Parent 10)

Parents believed they lacked adequate psychosocial strategies to support their child.

“We weren’t talking about it, because she didn’t want to talk about it, because she didn’t want to think about it.” (Parent 11)

“I think the fear of surgery and then just the level of pain and trying to help him as much as we could, but not really having a lot of tools really was anxiety for us.” (Parent 2)

Families were unprepared for surgery and postsurgical pain—Despite overall satisfaction with perioperative care, families felt that surgical preparation did not accurately reflect the experience. Families particularly perceived that pain severity was not accurately described by health care professionals, and expressed dissatisfaction that pain was under- or overstated. Families also reflected that no amount of information could have adequately prepared them for the challenge of surgery.

“I don’t think I was ready for... the pain and how I was going to feel that whole time. I think that’s just individual experience, I don’t know if they could kind of you know, answer that kind of question for me, how I was going to feel and the pain levels.... It was really kind of overwhelming at some points. So I don’t think I was prepared for that.” (Child 7)

Families desired more detailed information about the surgical experience. Specifically, they wanted more information about pain medication, including medication scheduling, weaning, side effects, and addiction following discharge. Families derived comfort from the detailed information they did receive, and perceived unexpected challenges could have been addressed beforehand to reduce anxiety.

Recovery and regaining physical functioning at home was challenging—

Children and parents reported their perception of the surgery recovery timeline did not meet their expectations. Families desired additional information about recovery and resuming activity. Children were uncertain about safety during activity and feared re-injury, impacting their physical recovery.

“Like right now she should be able to do things... but she’s scared something’s going to break or something is going to cause her pain. And she’s scared how far she can push.” (Parent 10)

Children were frustrated with limitations to activities of daily living and resulting dependence on parents. Parents were distressed by their children’s increased reliance during the recovery period, and struggled to balance their family roles and responsibilities while caring for their child.

“My most challenging part was waking up every 2 hours to give him the medication....I felt like I had a newborn again and I’m way too old to do that.” (Parent 3)

Children also experienced unexpected difficulties sleeping due to pain, anxiety and discomfort.

“Sleeping was really hard...It took me so long to become comfortable and then I would wake up another 2 hours later and be uncomfortable.” (Child 2)

Families struggled to return to valued activities—Throughout recovery, children struggled with missing out on valued activities of teenage life. In particular they missed sports and seeing their friends every day. Children were eager to regain independence (e.g., driving for older adolescents) and spend time with friends.

What I was really upset about was that I would have to skip the season before of softball and that's a big thing in my life. (Child 10)

Children were concerned about return to school, and when they did resume school attendance, they struggled with the regular requirements of a school day (e.g., walking in the hallway, sitting in class), keeping up with schoolwork, and ongoing fear of re-injury. Families noted that making arrangements with the school helped ease return.

“Sitting in class is something that's been harder... I don't really know how to correct that for myself and be able to be, like, super engaged and listening the whole time.” (Child 11)

Families reported interest in a perioperative psychosocial intervention—Families were interested in learning coping skills and receiving more detailed information about the perioperative experience. Families expressed preference for a presurgical program, and also desired additional postsurgical follow-up. Families were amenable to both in-person and remote delivery (e.g., web-based) of an intervention program, though emphasized the importance of individualization of content. Parents and children desired opportunities to connect with others going through surgery for reassurance, normalization and information. Families identified distance and time as potential barriers to participation in a psychosocial intervention.

“I think it would have been helpful to learn from people who have experienced it before... that would have been probably the most helpful because you really get to, you know, instead of hearing from a doctor who has done the surgery, you get to hear firsthand from someone who had it done.... talk to them about how it affects them, the experiences they had after the surgery, just to get a better understanding, you know, what exactly will happen.” (Child 5)

Provider interviews

From the provider interviews, three themes were identified including, 1) families would benefit from enhanced coping skills, 2) families would benefit from more detailed preparatory information, and 3) flexible delivery of a psychosocial intervention at home would be ideal.

Families would benefit from enhanced coping skills—Providers believe a psychosocial intervention would help families by providing strategies for coping with physical discomfort and psychological distress in the hospital. Providers feel ill-equipped to support children who are coping poorly and believe that providing effective coping skills will empower children to positively influence their recovery.

“I know that they’re going to have pain...but I don’t really know how to [help them cope better]...other than really try and reassure them that it’s going to get better.”
(Surgeon 1)

Providers note that parents often struggle to cope effectively in the hospital, particularly with their own anxiety about their child’s surgery and pain. They believe parents need coping strategies for reducing their own distress, guidance for supporting children in their coping efforts, and communication skills to more effectively advocate for their child with medical providers.

“We get kids that are in here with their parents who are three times as anxious as they are.” (Child Life Specialist 2)

“I think giving children those tools and as well as giving parents those tools ... taking away that unknown or not feeling empowered. Giving them that ability to know what they can do and giving them a... plan I think would just make the families feel better.” (Pre-Anesthesia Clinic Provider 3)

Families would benefit from more detailed preparatory information—Providers feel that standard surgical preparation is insufficient, and emphasized that families need more comprehensive and detailed information about what to expect over the entire course of surgery and recovery.

“I think many families don’t have a lot of information about what to expect...They have a lot of information typically about the surgery and what’s going to be done. I don’t think they have quite as much information about sort of the post-op period.”
(Pre-Anesthesia Clinic Provider 1)

They recommended including information about realistic expectations of pain and recovery, what to expect at the hospital, and education about pain medication.

“I think just giving them a realistic view [of pain] and what they can do to help with that pain.” (Surgery Clinic Nurse 1)

“What you can do in the first week that you’re home, the first month that you’re home, the first six months, the first year.” (Child Life Specialist 2)

Flexible delivery of a psychosocial intervention at home would be ideal—Providers believe a psychosocial intervention would be feasible to families, and would address gaps in standard perioperative preparation. Providers advocated for a program that is cohesive, noting that many families struggle to understand and retain information currently provided.

“It’s so hard to know if we’re doing what we need to do at the pre-op because sometimes they just seem kind of overwhelmed... I feel like they’re so focused on just getting through one step first.” (Pre- Anesthesia Clinic Provider 2)

“Maybe they were told [something about the surgery] and either they didn’t remember or they weren’t told in a way that they understood.” (Inpatient Surgery Nurse 5)

Providers identified the presurgical period as the ideal window for intervention delivery, with the option of postsurgical follow-up. They suggested offering multiple delivery platforms (e.g., web-based, mobile app, in person). They stressed the benefit of providing a forum for families to ask questions to healthcare providers and provide access to a variety of resources.

“Having the resources once they leave and they’re at home in an environment where they feel safe and comfortable gives them a chance to re-process, re-absorb information... practice it and sometimes not be overwhelmed by the environment.”
(Child Life Specialist 2)

Providers emphasized time and access to care as potential barriers to intervention delivery. In addition they raised skepticism, stigma and lack of interest as potential barriers. They highlighted that an intervention program should be developmentally appropriate and individualized, as well as accessible to patients regardless of language. Accordingly, they believe a web-based program could improve accessibility, though expressed some concern it would not be sufficiently engaging or personalized.

DISCUSSION

This study provides an in depth description of families’ experience of long-term pain and recovery after major surgery, and identifies potential barriers and facilitators of intervention delivery in the perioperative period. Children and parents experienced major surgery as a stressful event, including the weeks leading up to surgery and extending long after their return home. Families felt under-prepared for surgery, particularly in terms of expectations regarding pain and physical recovery; children and parents expressed a need for coping skills during this time. Families and healthcare providers expressed interest in a preoperative psychosocial intervention teaching coping skills prior to surgery.

Our findings that families experienced the perioperative period as highly stressful, experiencing worry and fear about pain and complications, extends prior research exploring anxiety in children and parents prior to surgery^{25,26}. We identified worry and anxiety, parental guilt, fear of pain, and fear of re-injury as potentially modifiable psychosocial targets for a perioperative intervention. Taken together with research identifying anxiety and pain catastrophizing in children and parents as influencing long-term outcomes after major pediatric surgery^{6,17,21}, these findings highlight the need to develop preoperative interventions targeting anxiety.

Families also experience challenges related to the child’s long-term recovery and experience of postsurgical pain. Uncertainty about safety during the weeks and months following surgery impacted children’s recovery and return to activities; thus families desired more information about what to expect to aid the child’s return to physical activities and reduce fear of re-injury. Both parents and children experienced trouble sleeping both before and after surgery and suggested that sleep disruption interfered with recovery at home after surgery. Recent research in children found high rates of insomnia in children after surgery, and identified significant relationships between sleep and next day pain²². Our current

findings further underscore the critical need for research addressing sleep deficiency in children undergoing surgery.

Participants expressed the desire to “know everything,” desiring detailed information about surgery, pain, and recovery. Current preoperative preparation for children generally focuses on helping families understand the hospital logistics and the acute recovery experience, whereas we found that families desire more understanding of the recovery over the weeks and months after surgery. Variability was found in children’s experience of pain and recovery after surgery. While some families felt pain was overstated others felt it had been understated; some even noted it would not be possible to prepare someone for what they had experienced. Indeed it may not be possible to provide accurate expectations on all aspects of the recovery experience, particularly pain, as the course of recovery from major surgery can be unpredictable for some children. Families expressed need for normalization and reassurance, which they strongly believed would be best delivered by someone who could relate to their experience on a personal level, rather than members of the medical team. Connecting with other children and families who previously underwent similar major surgery may provide this reassurance and normalization experience to families.

Research examining education interventions prior to surgery indicate that delivery of education alone without providing coping skills may actually increase anxiety and distress²³. Limited research has examined interventions providing coping strategies for adolescents undergoing major surgery. These similarly focus on decreasing in-hospital anxiety and short-term pain^{7,11,12}. Two studies have examined the effect of interventions targeting pain in adolescents beyond 72 hours^{4,12}. Both studies delivered the intervention by video the day before surgery; one provided coping skills¹², and the other provided instruction in relaxation and imagery⁴, with inconsistent results. In a meta-analysis⁷, these brief presurgical interventions had no effect on pain after 72 hours. In younger pre-school age children undergoing day surgery, web-based delivery of coping skills has been effective in reducing short-term anxiety¹⁰. In adults undergoing spinal fusion surgery, incorporation of cognitive behavioral-based interventions^{1,14} and structured meetings with other patients⁵ into rehabilitation after surgery was successful in reducing catastrophizing, pain and disability in the first several months following surgery. One study has examined delivery of a cognitive-behavioral intervention in adults before surgery, finding no improvement in 12 month outcomes²⁴. Trials are currently underway examining the effect of preoperative delivery of cognitive-behavioral therapy before major spine surgery on disability and pain in adults¹³. The findings of the present study can further inform intervention development and extend existing interventions with the aim of improving recovery at long-term follow-up for older children and adolescents undergoing major surgeries.

Providers and families identified distance and time as potential barriers to engagement in psychosocial interventions before surgery. While providers raised family skepticism or lack of interest as potential barriers, families did not raise this concern and expressed that they would be open to a psychosocial intervention. As suggested by both families and providers, remote delivery through technology can potentially overcome intervention delivery barriers of distance and time, and may therefore be ideally suited to the context of surgery. Indeed, web-based delivery of cognitive behavioral therapy to families has been shown to be feasible

and effective in managing children's chronic pain^{9,19}. Research to extend such interventions for children having major surgery is critically needed.

The findings of this study should be considered in the light of the following limitations. First, while we included multiple stakeholder groups, participants were sampled from a single pediatric specialty hospital, and included only those undergoing major surgery. Therefore findings cannot be generalized to other settings. However, given that our study was conducted at a specialty children's hospital, it could be postulated that children undergoing surgery in other settings may experience greater gaps in preparation when undergoing surgery. Second, our sample had limited sociodemographic diversity, and parents were mostly mothers. Emerging research has identified unique challenges in underserved children undergoing surgery¹⁶. Nevertheless, we sought perspectives from children and their parents, as well as clinicians with diverse expertise in order to identify potential opportunities to improve care. Third, we used an explicit rather than implicit level of analysis for coding qualitative interviews, which limits our findings to descriptions of participants' experiences rather than generating a theory to apply to the data.

This research also has implications for assessment of treatment outcomes of interventions aimed at improving long-term postsurgical outcomes. Children's experiences highlight that assessment of treatment outcomes need to be relevant to their context of surgery. For example, youth and their families identified vulnerability, independence, resumption of valued activities including school and sport, and social reintegration as areas of impact. Mixed methods may need to be employed and new measures may need to be developed to capture context specific health and functional outcomes in children after surgery. Such measures might be included in future intervention studies in this population.

In conclusion, families and healthcare providers desired a perioperative intervention providing more detailed and consistent preparation for surgery, focusing on challenges with pain and recovery, and teaching coping skills to help children and parents deal with the unique stressors around major surgery. Future research developing interventions to address these areas is critically needed.

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PERSPECTIVE

This qualitative study examined children and their parents' experience of long-term pain and recovery after major surgery, identifying barriers and facilitators of perioperative intervention delivery. Families experienced surgery as stressful, and felt under-prepared for pain and recovery. Families and healthcare providers expressed interest in a preoperative intervention teaching coping skills.

- Families experienced major surgery as a stressful event, well beyond return home.
- Families felt under-prepared for surgery, particularly pain and physical recovery.
- Families and providers were interested in a preoperative psychosocial intervention.
- Flexible delivery of an intervention teaching coping skills at home would be ideal.

Table 1

Characteristics of Family Participants

<i>CHARACTERISTIC</i>	<i>MEAN (RANGE)</i>	<i>N (%)</i>
Age at time of surgery (years)	15.4 (12.2–18.9)	
Teen Sex		
Female		9 (60)
Male		6 (40)
Teen Race		
White		14 (93.3)
Black		1 (6.7)
Type of surgery		
Spinal Fusion		7 (46.7)
Pectus Repair		7 (46.7)
Hip Osteotomy		1 (6.7)
Time from surgery to interview (days)	180 (93–312)	
Parent relationship to child		
Mother		13 (86.7)
Father		1 (6.7)
Grandmother		1 (6.7)
Parental Marital Status		
Married		11 (73.3)
Divorced		2 (13.3)
Never Married		2 (13.3)
Family Income		
< \$49,999		3 (20)
\$50,000 – \$100,000		3 (20)
> \$100,000		9 (60)

Table 2

Examples of Questions and Probes from Semi-structured Interview Guides for Family and Provider Participants

<i>DOMAIN</i>	<i>FAMILY</i>	<i>PROVIDER</i>
Perioperative challenges	What was the most challenging part of the surgical experience for you? Was there anything you felt like you were not prepared for?	Do you think the hospital does a good job before surgery with preparing and helping children and their families to cope after surgery? In what ways?
Emotional experience	Did any thoughts or worries bother you before surgery? Did any thoughts or worries bother you after surgery? Did you do or say anything to stay positive?	How do you think children and their families cope with major surgeries and the pain and recovery that happen afterward?
Long-term recovery	How easy or hard was it to get back to your activities after you were better? Tell me about your return to school * What did your family need during this period to help recover?	What do you think families need during this time to help them reduce long-term problems?
Postoperative outcomes	Which outcomes related to surgery were most important to you?	
Interest in perioperative psychosocial intervention	Do you think children and their families would benefit from a program aimed at preparing families to manage and cope with pain and anxiety after surgery? Why/why not? Would a two-hour in person workshop be useful? Why/why not? Would an interactive website be useful? Why/why not?	Do you think children and their families would benefit from a program aimed at preparing families to manage and cope with pain and anxiety after surgery? Would a two-hour in person workshop be useful? Would an interactive website be useful?
Potential barriers to participating in a perioperative psychosocial intervention	What might have prevented your family from participating in such a program?	What do you anticipate potential barriers to either the child or parents' participation in a psychosocial intervention for pain and anxiety could be?

* Probe added based on initial analysis of interview data concurrent with data collection