

Procedural pain in children: A qualitative study of caregiver experiences and information needs

by

Kassi Shave

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## Abstract

**Background:** Procedural pain is the unpleasant sensory and emotional experience children endure when undergoing a medically situated intervention that may cause pain, anxiety, or distress. Procedural pain is a major contributor to every child's experience with acute pain. Poorly managed procedural pain can have short-term and long-term impacts for a child, which can extend and complicate both the procedure and the emergency department (ED) stay. There are many evidence-based physical, pharmacological, and psychological interventions available to manage pain and distress in children undergoing procedures; however, they are under-utilized across Canadian EDs. Knowledge translation (KT) tools are essential to ensure the uptake of evidence in practice. The objective of this study was to actively collaborate with caregivers of children experiencing procedural pain in the ED, and gather information to inform the development of a novel, caregiver-focused KT tool for management strategies for procedural pain.

**Methods:** Qualitative semi-structured interviews were conducted with a purposeful sample of caregivers of children who attended the ED at the *Stollery Children's Hospital*. Our target for this study was children who underwent IV placement or venipuncture within 4 hours prior to the interview. Caregivers of children ages 3 to 12 years were included. Based on previous qualitative research, we anticipated approximately 10-15 interviews would be required to see saturation of the data. Questions moved from general to specific, with interviews later in the data collection period becoming increasingly focused. The interviews were audio-recorded and transcribed verbatim. Data analysis was facilitated through the use of NVivo 10.

The key stakeholder for this research project was Translating Emergency Knowledge for Kids (TREKK), a National Centre of Excellence in Knowledge Mobilization. TREKK has a parent advisory group that provides input on all TREKK activities, and was involved in and provided feedback throughout the study.

**Results:** Caregivers (n=12) were interviewed in the ED at the Stollery Children's Hospital. Interviews were conducted within four hours of the child having an IV or venipuncture procedure, and the mean length of interview was 18 minutes. On average, caregivers were caucasian (n=11) mothers (n=9) between the ages of 30-41 (n=11) who were married (n=9), had received a post-secondary education, and reported a household income of >\$90,000 per annum. The children of participants in our study were, on average, 7 years old, had an intravenous insertion procedure, and had a history of a chronic medical condition, as described by their caregiver.

Analysis of the interviews revealed five major themes: 1) source of healthcare information; 2) delivering healthcare information; 3) communicating with caregivers; 4) procedure-related anxiety and long-term effects; and 5) advice from caregivers. Caregivers expressed that they want to receive information from their healthcare provider, and want the information to be directed at their child. Caregivers recommended the following methods for sharing healthcare information with children: treating children as someone who is going to understand, ensuring children know what to expect, describing the procedure using language and concepts that are familiar to children, giving children processing time, and involving children in the procedure. Caregivers wanted to be empowered to ask informed questions of their healthcare providers. Finally, caregivers in our sample consistently negative experiences with intravenous insertion

and venipuncture procedures for their children, occurring mainly at urban and rural non-pediatric centres.

**Conclusions:** Given that 85% of Canadian children in need of emergency care are seen in non-pediatric EDs, our study supports the need for KT efforts targeting the general ED setting. This research generated key knowledge through collaborative researcher-stakeholder partnerships, and will form the foundation for the development of a KT tool that may empower patients and their caregivers to play an active role in their healthcare. Ensuring patient and caregiver access to essential health information is critical for enhanced, family-centered, healthcare delivery and improved child health outcomes.

## **Preface**

This thesis is an original work by Kassi Shave. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Ethics Board, Project Name “PROCEDURAL PAIN IN CHILDREN: A QUALITATIVE STUDY OF CAREGIVER EXPERIENCES AND INFORMATION NEEDS”, No. Pro00056710, 9/16/2015.

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**List of Abbreviations**

**ED** – Emergency department

**IV** – Intravenous

**KT** – Knowledge translation

## **Chapter 1: Background**

Pain is a complex phenomenon, and its proper management is becoming increasingly recognized as the cornerstone of high-quality patient care [1-3]. Optimizing the treatment of pediatric pain has been highlighted as a key healthcare priority by the World Health Organization, among other leading pediatric and pain societies internationally [1, 4-7]. There are many different kinds of pain (e.g., chronic, acute, and procedural pain), with procedural pain being most common in children [8]. Children experience multiple painful procedures daily when being cared for in hospital and ambulatory settings [9-12]. Further, with half of all emergency department (ED) visits resulting from painful conditions, and 78% of patients experiencing pain during their ED stay [13], EDs represent a setting where effective pediatric pain management should be an essential component of care. Children frequently undergo a variety of painful procedures in the ED, the most common being: venipuncture, intravenous (IV) insertions, capillary blood sampling, urinary catheterization, intramuscular injections, lumbar puncture, laceration repair, nasogastric tube insertion, nasal aspiration, joint aspiration, and burn dressings [4]. Despite the frequency of these procedures in children, there remains sub-optimal pain management for these vulnerable individuals [1, 2, 14-17].

### **1.1 Understanding pediatric pain**

Pain is a phenomenon that is subjectively experienced by each child. Pain response is shaped by both genetic and environmentally determined factors [8]. Non-modifiable determinants of pain exist prior to the procedure, and include factors like age, development, sex, and ethnicity [8]. On average, children who are young, female, at a lower developmental stage, and/or are of black or Hispanic ethnicity rate pain higher than do older, developed, male,

Caucasian children [8]. Pain sensitivity, coping, and anxiety are all determinants of pain that, with intervention, are modifiable over time. Young [8] suggests behavioural anxiety-reduction techniques, teaching of adaptive coping skills, and caregiver education may have utility for pain sensitive children. A number of modifiable procedure-related factors can also impact a child's pain response. In most cases, having caregivers present, instructing caregivers on positive behaviours that can be used during painful procedures, providing children with information, and using a combination of pharmacological and non-pharmacological evidence-based interventions for pain management, can all reduce ratings of pain [8].

## **1.2 Impact of pediatric procedural pain**

Procedural pain makes up the majority of the typical child's experience with acute pain [8]. Of painful procedures, venipuncture and IV insertions represent the two most common sources of pain in children receiving hospital care [18]. Poorly managed pain from these procedures can have short-term impacts on a child, including anxiety, avoidance behaviours, and somatic symptoms, which can extend and complicate both the procedure and the ED stay. In the long-term, children who experience procedural pain are more likely to be distressed by future painful procedures [19]. Children who are fearful of, and experience pain from needle procedures are more likely to have increased pain sensitivity, fear, and are more likely to avoid seeking healthcare as adults [18]. Additionally, approximately 10% of the population experience needle phobia, which is in part linked to genetic predisposition and environmental factors, like negative experiences with needle-related pain in childhood [18, 20]. Those with needle phobia not only experience extreme adverse physiological responses to needle procedures, but also have increased morbidity and mortality due to persistent avoidance of medical care throughout their

lifespan [18, 20]. Further, poorly managed procedural pain early in life may also negatively impact immune function and neurophysiological development [8].

Caregivers may also experience anxiety and are distressed by their child's painful procedure, which, in turn, may increase their child's perceived pain [21]. In an observational study of 55 caregivers of children aged 1 to 18 years, caregivers who watched their child experience an IV insertion had an elevated heart rate, blood pressure, and self-reported their anxiety to be greater than baseline [21]. Increased heart rate, blood pressure, and anxiety positively predicted increased child pain and distress, and caregiver distress-promoting behaviours accounted for over 50% of the variability in the child's distress during post-procedure recovery [21]. Caregiver distress about their child's needle procedures is also linked to poor adherence to vaccination schedules and avoidance of future healthcare [22-24].

### **1.3 Interventions to manage procedural pain**

There are many evidence-based pharmacological and non-pharmacological interventions available to manage pain and distress in children undergoing procedures [4]. Effectiveness of the specific interventions is age-dependent.

#### **1.3.1 Pharmacological interventions.**

For needle-related procedural pain in children and/or neonates, use of topical anesthetics and sucrose or other sweet-tasting solutions are widely supported by the literature [4, 7, 10, 22]. Topical anesthetics work to reduce the needle-related pain associated with procedures such as venipuncture or IV insertions by creating a numbing effect at the procedure site [22]. Liposomal lidocaine (Maxilene) and tetracaine (Ametop) are recommended for the ED setting because they provide potentially greater pain relief and are faster-acting than other comparable anesthetics

[22]. This is beneficial in the ED setting given the time-constraints experienced by healthcare providers as well as to reduce waiting time for patients and their families. The primary limitation of topical anesthetic use in the ED context is that the anesthetics cannot be effectively utilized if the procedure is emergent and must be done quickly. Liposomal lidocaine and tetracaine need to be applied at least 30 minutes prior to a procedure to provide optimal pain relief [22]. Sucrose and other sweet-tasting solutions have robust evidence supporting their use in neonates, and have been suggested for use in infants until 12 months of age [22].

### **1.3.2 Non-pharmacological interventions.**

There are many psychological interventions available for managing procedural pain in children. These interventions can be either cognitive or behavioural in their approach, and are best used in addition to a pharmacological intervention [22]. Cognitive strategies target mechanisms that alter a child's ability to perceive pain [22, 25]. Potential strategies may include distraction, cognitive therapy, hypnosis, suggestion, coping skills training, modelling, memory alteration, thought stopping, and imagery [4]. There is strong evidence to support the use of hypnosis and distraction to reduce needle-related procedural pain and distress in children [26]. Distraction techniques including music, video games, and videos have been specifically demonstrated as efficacious at reducing children's self-reported anxiety and distress in the pediatric ED setting [22, 27, 28].

Behavioural strategies typically involve the caregiver either directly or indirectly physically interacting with their child [22, 25]. Potential strategies may include the caregiver preparing their child for a procedure, being present for a procedure, facilitating progressive muscle relaxation training, and/or encouraging the use of breathing exercises [4]. In infants,

behavioural interventions can include the caregiver rocking or holding the child, kangaroo care/skin-to-skin contact, swaddling/facilitated tucking, non-nutritive sucking (e.g., providing a child with a pacifier), breastfeeding, massage, and caregiver presence [4]. For neonates, evidence-based behavioural strategies for reducing procedural pain include breastfeeding, nonnutritive sucking, and swaddling [22].

#### **1.4 Procedural pain management in Canadian EDs**

Despite the availability of numerous evidence-based interventions for children experiencing procedural pain, their use varies significantly across Canadian EDs [29], and procedural pain remains widely undertreated. Patients receiving care across a variety of healthcare settings continue to report, in many cases, avoidable moderate to severe pain [5]. In a recently conducted prospective survey of Canadian pediatric emergency physicians, 53% reported IV insertion procedures were never or rarely carried out with analgesia [29]. Only 25% of physicians reported using non-pharmacological interventions (including distraction, swaddling, oral sucrose, and breastfeeding) for venipuncture procedures [29]. Only 5% of pediatric emergency physicians reported their department using a nurse-initiated pain treatment protocol for topical anesthetics prior to IV insertion [29]. Similarly, an Alberta-specific study indicated few EDs have policies and protocols in place specific to management of procedural pain in children [30].

Inadequate pain management remains a persisting issue in Canadian pediatric EDs for a number of reasons. Pain is commonly underestimated due to a lack of developmentally appropriate assessment tools [31]. Because of the subjective nature of pain, its link to developmental stage and age, and children's limited ability to communicate and differentiate



between pain and anxiety, accurately measuring and assessing pain is complex [2]. On the whole, pain management has been insufficiently addressed in both undergraduate and graduate medical education [31, 32]. Canadian emergency medicine residents report having received insufficient training to adequately manage pain in children, and identify particular concern when working with infants or children with developmental disability [33]. Lack of education may contribute to physicians' reported fears of over-sedation, respiratory depression, addiction, and/or unfamiliarity with the use of sedatives and analgesics when treating a child experiencing pain [31]. The fast pace and busy environment of the ED also perpetuate patient and caregiver anxiety and increase perception of pain, complicating its adequate treatment [34]. Time constraints also contribute to the underutilization of topical anesthetics. Physicians express concern about delaying diagnostic procedures, subsequent delay in diagnosis and treatment, as well as lack of availability or cost of anesthesia and/or analgesia [31]. These concerns are likely to be exacerbated in non-pediatric healthcare settings (e.g., general emergency departments, phlebotomy labs) where pain management in children is less optimal [30], and healthcare providers have received substantially less training in pediatric-specific care.

To improve pain management in pediatric ED physicians identified key priorities: needing increased access to drugs, improved policies and procedures focusing on pain management at their institution, and further education about evidence-based pain management, psychological interventions, and procedural sedation practices and drugs [3].

### **1.5 Procedural pain is a knowledge translation issue**

A gap exists between the publication of health evidence, and bringing evidence-based research into everyday practice. Simply publishing evidence from clinical research fails to

catalyze change in medical practice [35]. Canadian healthcare providers are not utilizing well-established, effective, readily available, and minimally invasive pain management interventions when caring for children experiencing the most common painful procedures, IV insertions and venipuncture, in the ED. The need for knowledge translation research focusing on identifying and evaluating methods of bringing procedural pain management evidence to the bedside is evident, and has been echoed across the pediatric pain literature [1, 3, 4, 7, 9, 13]. The American Academy of Pediatrics and the American Pain Society have jointly emphasized the need for physicians treating children to assume a leadership and advocacy role to ensure adequate treatment of procedural pain in infants, children, and adolescents [1].

Knowledge translation (KT) tools are essential to ensure the uptake of evidence in practice. A number of different approaches to translating research evidence into practice have been described in the literature across various medical conditions and healthcare settings (e.g., clinical practice guidelines, storybooks, educational interventions) [36-38]. Many of these strategies have been utilized to translate pain management evidence [39-42]; however, the vast majority of these KT approaches have targeted healthcare providers, and have not been specific to the ED context [41-45]. A recently conducted systematic review of knowledge translation in pediatric pain focusing on healthcare providers indicated that although many studies have reported increases in comfort, confidence, knowledge, and skills, practice-level changes occurred with varying success, and little focus was given to the long term impact and sustainability of outcomes [46]. More recently, attention has turned to engaging caregivers, and several Canadian studies are being conducted targeting educating and empowering caregivers (e.g., parents, family members, legal guardians) of children undergoing painful procedures [47-49]. Little research has been done specifically in the context of the pediatric ED.

## **1.6 Patient engagement**

Considering the wide availability of evidence-based physical, pharmacological, and psychological interventions to reduce and/or eliminate procedural pain, procedural pain in the ED should be a largely preventable and unnecessary experience for sick or injured children. Ensuring both children and their caregivers can access essential, often complex healthcare information, is critical to facilitating an active partnership in their care. The American Academy of Pediatrics and the American Pain Society jointly highlight the need for information to be provided to children and families so they know what to expect when a child is having a painful procedure, and so caregivers are prepared with specific strategies to minimize distress and comfort their children [1, 50]. Adequately preparing caregivers for procedures not only results in less distressed caregivers, but also decreases child anxiety [4, 51, 52].

Caregivers of children undergoing painful procedures in the ED demonstrate interest and commitment to ensuring their child has a pain free experience. In a prospective survey of caregivers presenting in an ED with a child 8 years of age or under, 89% of caregivers indicated that they would choose to make their child's IV insertion painless, and of those caregivers, 65% indicated that they would spend an extra hour in the ED if required to make their child's IV insertion painless [53]. Willingness to stay was independent of income and ethnicity [53]. As EDs across North America continue to face time and resource constraints, including long wait times and high patient volumes, caregivers represent a captive audience who is motivated to eliminate the pain their children face when undergoing painful procedures and in most cases, has the time to have a role in doing so [54-58].

## **1.7 Study objectives**

The first step to engaging caregivers in managing children's procedural pain is to gather information on their perspectives and needs. The objectives of this study were to determine: (1) what are caregivers' experiences around painful medical procedures; (2) what are caregivers' information needs regarding procedural pain and how they can help manage it; and (3) what format do caregivers want to receive information about procedural pain. This research will generate new knowledge through collaborative researcher-stakeholder partnerships, and form the foundation for the development of a KT tool that will empower patients and their caregivers to play an active role in their healthcare. Ensuring patient and caregiver access to essential health information is critical for enhanced, family-centred, healthcare delivery and improved child health outcomes. This work will serve as a model for developing KT interventions in other clinical areas. Moreover, the results of this work may have implications beyond the ED, given the prevalence of these procedures across numerous health settings.

## **Chapter 2: Methods**

### **2.1 Study Design**

#### **2.1.1 Qualitative description.**

A qualitative descriptive methodology was used in this study. Qualitative description lends itself well to our study objectives for two reasons. First, Braun & Clarke (2014) highlight, “Qualitative research offers rich and compelling insights into the real worlds, experiences, and perspectives of patients and health care professionals in ways that are completely different to, but also sometimes complementary to, the knowledge we can obtain through quantitative methods” [59]. Key to our study, qualitative research provides holistic data, rich in description and rooted in real life contexts, that go beyond the scope of what would be achievable conducting quantitative research [60]. Second, descriptive studies provide a detailed summary of an event as it was experienced by a person, in the words of that person [61]. Further, Sandelowski [61] emphasizes, “Qualitative description is especially amenable to obtaining straight and largely unadorned (i.e., minimally theorized or otherwise transformed or spun) answers to questions of special relevance to practitioners and policy makers” (p. 337). Given the primary aim of this study was to acquire detailed descriptions of caregiver experiences, as described by caregivers, when their child has had an IV insertion or venipuncture procedure in the emergency department, qualitative description resonated well with our intended objectives.

#### **2.1.2 Theoretical/philosophical orientation.**

While Sandelowski [61] described qualitative description as “minimally theorized”, it is not without a philosophical orientation [61, 62]. Qualitative description draws on the tenets of naturalistic inquiry, an approach that emphasizes, to the best of one’s ability, studying a person

or object in its natural state. In keeping with naturalistic inquiry, variables were not pre-selected or manipulated, and no *a priori* commitment was made to any view of our target phenomenon [61, 62].

## 2.2 Sample

Caregivers of children between the ages of 3-12 who had undergone an IV insertion or venipuncture procedure at the Stollery Children's Hospital Emergency Department in the 4 hours prior to recruitment were invited to participate in this study. The Stollery Children's Hospital is a full service specialized pediatric center located in a large Canadian metropolitan center (Edmonton, Alberta). The Stollery Children's Hospital is the Western Canada referral center for pediatric cardiac surgery and a national leader in organ transplantation [63]. Consequently, 40% of patients at the Stollery Children's Hospital come from outside the Edmonton region [64]. The emergency department is a 24 bed facility that accommodated over 48,500 emergency department visits in the 2014-15 year [64].

Purposive sampling was utilized to generate an in depth understanding of caregiver experiences when a child has had an IV insertion or venipuncture procedure in the emergency department [65]. In keeping with qualitative tradition, no specific *a priori* sample size was defined prior to conducting the interviews. Sample size was determined by saturation of the data, which was monitored through concurrent analysis of the data to assess comprehensiveness, variation, and richness of the interviews [66]. Saturation was defined as the point at which no new information is obtained through the collection of data from subsequent participants [66]. Based on previous qualitative research, we anticipated that approximately 10-15 interviews would be needed to see saturation [67].

### **2.2.1 Inclusion criteria.**

Caregivers were eligible to participate in the study if they (a) identified themselves as the child's primary caregiver; (b) the caregiver's child was between the ages of 3-12 years old at the time of the interview; and (c) the caregiver's child had an IV insertion and/or venipuncture procedure completed in the preceding 4 hours. The primary caregiver was defined as an individual who self-identified as the principal provider of care and attention to the child. Thus, caregivers with diverse relations to their children were eligible to participate in this study (e.g., biological parents, adoptive parents, foster parents, grandparents). Children between the ages of 3-12 years old were selected to participate in this study as an effort to homogenize our sample – infants and adolescents are at very different developmental trajectories, and thus would likely have vastly different needs and experiences with procedural pain in the ED. IV insertion and venipuncture procedures were chosen because they are amongst the most common medical procedures in both healthy and ill children [68], and needle procedures are reported to be one of the most painful experiences for children [69, 70]. The time period of 4 hours was implemented to reduce recall bias, while allowing sufficient time to meet with participants without interrupting or negatively impacting medical care.

### **2.2.2 Exclusion criteria.**

Caregivers were excluded from the study if they (a) had a child with urgent medical needs, as determined by the treating emergency department team; (b) were non-English speaking; or (c) previously participated in this study. Children with urgent medical needs were excluded from this study as to not interrupt or obstruct medical care, or cause further distress to the child's caregiver. Urgent medical needs were defined as the child: is in critical condition,

requires emergent IV placement or venipuncture, has an altered level of consciousness, or for any other reason as determined by the treating emergency department team. Because of the qualitative nature of this study, potential participants who were unable to understand and/or communicate in English were excluded. Caregivers could only participate once in this study so we could best reflect a diversity of caregiver experiences in the emergency department.

### **2.2.3 Recruitment.**

Study recruitment occurred between October 2015 and December 2015. Institutional approval was obtained for this study from the University of Alberta Health Research Ethics Board (Pro00056710) (Edmonton, Alberta, Canada), as well as operational approval from the Stollery Children's Hospital (Edmonton, Alberta, Canada), and administrative approval from Alberta Health Services (Edmonton, Alberta, Canada).

All caregivers of children ages 3-12 years old who had undergone an IV insertion or venipuncture procedure in the preceding 4 hours in the emergency department at the Stollery Children's Hospital were identified and approached by a physician or nurse on staff when the graduate student (KS) was present and available for data collection in the emergency department. The physician or nurse on staff asked the caregivers if a researcher could approach and speak to them about participating in a study. Upon agreement, the graduate student (KS) approached the caregiver to confirm eligibility and invite them to participate in the study. If caregivers expressed interest in participating in the study, a letter of initial contact (found in **Appendix A**) was provided to the potential participant, who was then given time to read the letter and ask any questions. After reading the letter of initial contact, the participant was asked if they wished to participate in the study. Written informed consent was obtained from all caregivers who agreed



to participate in the study. At the end of the study, all caregivers were offered a \$10.00 Tim Horton's Gift Card as a token of thanks.

#### **2.2.4 Participants.**

In total, 17 caregivers were invited to participate in this study in the emergency department at the Stollery Children's Hospital. Of those invited, 5 caregivers refused consent because they were not interested in participating, and 12 caregivers were successfully recruited and participated in this study. The rate of participation was 71%. Of the 12 caregivers recruited, 11 participated to the point of completion of the interview. One interview was interrupted half-way through because their child had urgent medical needs, as defined in the study exclusion criteria. Permission was obtained from this caregiver to use the data that had been collected prior to the point of ending the interview. The graduate student (KS) conducted all 12 of the caregiver interviews.

#### **2.3 Stakeholder Engagement.**

The key stakeholder for this research is Translating Emergency Knowledge for Kids (TREKK), a National Centre of Excellence in Knowledge Mobilization. TREKK is a growing network of researchers, clinicians, national organizations and health consumers who are collectively working to improve emergency care for children across Canada. To do this, TREKK collaborates with over 30 general emergency departments across Canada, spanning 9 provinces and 1 territory. TREKK has a parent advisory group that provides input on all TREKK activities, and was involved in and provided feedback throughout the study. The parent advisory group is comprised of parents of children with diverse health needs and experiences. Meetings were held with this group during the course of the project to gather input on interview guide development

and piloting, data collection, analysis of the data, interpretation of the results, and development of next steps.

## **2.4 Data Collection**

### **2.4.1 Demographic variables.**

Demographic data for all participants and children were collected verbally at the outset of the interviews using a standardized question guide (found in **Appendix B**). Data was collected on the following variables: age, marital status, occupation, education, household income, and ethnicity. Caregivers were also asked to self-report the following information about their child: pre-existing medical conditions, previous serious illnesses, number of emergency department visits, number of hospital admissions, and number of IV insertions or venipuncture procedures. The above information was collected on all participants to describe the characteristics of our study sample.

### **2.4.2 Interviews.**

One-on-one, semi-structured interviews were conducted in the Stollery Children's Hospital Emergency Department. An interview guide was developed for reference throughout the interviews (found in **Appendix C**). The interview guide was pilot tested with 6 individuals, 4 of whom were research staff from the Department of Pediatrics at the University of Alberta that had no involvement in the project, and 2 of which were members of the parent advisory group of Translating Emergency Knowledge for Kids (TREKK), a part of the Networks for Centres of Excellence Knowledge Mobilization Initiative. All feedback provided by those who pilot tested the interview guide was incorporated prior to formal data collection in the emergency department. The TREKK parent advisory group provided feedback at key points during the data

collection progress, which resulted in the interview guide becoming increasingly specific as the study progressed.

Caregivers were given the option of being interviewed at their child's bedside or in a private room within the department. At the request of the caregivers, all interviews were conducted bedside with the child present. On average, caregiver interviews lasted 18 minutes and 24 seconds. The shortest interview was 6 minutes and 47 seconds, and the longest interview was 34 minutes and 49 seconds. All interviews were audio-recorded and transcribed verbatim. The interviewer (KS) regularly debriefed with the primary supervisor (LH) and member of the supervisory committee (SA) about interview progress and addressed any emerging questions.

## **2.5 Data Analysis**

All interview audio files were submitted electronically to Consentia Inc. ([www.consentia.com](http://www.consentia.com)), where the audios were de-identified and transcribed verbatim. A standard non-disclosure agreement was signed by all Consentia Inc. employees who came in contact with the audio files to protect the privacy of participants. Transcripts were uploaded into a qualitative data management software, NVivo 10 (QSR International; Melbourne, Australia), for analysis. Data analysis was initiated as transcripts were received from Consentia Inc., and was carried out by KS and LH. Transcription and analysis of the data occurred concurrently with interviews to monitor progress and permit follow-up of ideas that emerged [67, 71].

Braun & Clarke's [72] phases of thematic analysis were used to guide analysis of the data. First, familiarization with the data occurred [72]. All audios and transcripts were listened to and read simultaneously. Transcripts were then read individually, multiple times, and audios were referred back to for clarification and context when necessary. Memoing was used to

enhance the research process, specifically through mapping research activities, extracting meaning from the data, and maintaining momentum [73]. Initial thoughts and impressions were incorporated into the memos to aid analysis. Second, generating initial codes occurred [72]. Inclusion criteria for all codes were systematically defined to permit coherence throughout the collection of data for each code. Third, searching for themes occurred [72]. After all codes were developed, codes were collated into potential themes. Fourth, themes were reviewed on two levels [72]. All potential themes were first checked against coded quotes, and then second, against the entire data set, to ensure appropriate representation of the data. Additionally, memos were reviewed for verification of potential themes. Fifth, all themes were defined and named [72].

## **2.6 Methodological Rigor**

Guba's [74] naturalistic mode for dealing with questions of trustworthiness was used to guide methodological rigor in this study. The following criteria were examined: credibility, transferability, dependability, and confirmability.

### **2.6.1 Credibility.**

Credibility was addressed in a number of ways. Data collection occurred from October 2015 – December 2015. The graduate student (KS) was present in the emergency department to collect data for 8 hour shifts at varying times of day, evening, and night throughout the study, and no more than two participants were recruited during any one shift. This prolonged researcher engagement in the emergency department, ensured there was not an over concentration of certain respondents, and maximized the diversity of our sample. The graduate student (KS) regularly engaged in peer debriefing with LH and SA to discuss emerging ideas and challenges.

Additionally, triangulation was utilized throughout the study. Three investigators (LH, SA, SS) and one graduate student (KS) were actively involved in the project, which allowed for cross-checking of the data and interpretations made during the process of data analysis.

### **2.6.2 Transferability.**

Transferability was enhanced through: 1) collecting descriptive data; and 2) utilizing purposive sampling. First, data was collected on both the caregivers participating in our study, as well as their child of reference who underwent an IV insertion or venipuncture. Detailed demographic data was collected from the caregivers to clarify the characteristics of this sample, and information was elicited from all caregivers regarding their child to contextualize the child's overall health, emergency department visits, hospitalizations, and experiences with IV insertions and/or venipuncture procedures. These detailed descriptions permit comparison of our study context to other potential emergency department locations or health care contexts. Second, purposive sampling of caregivers in the emergency department based on child age, procedure, and timeframe of the procedure, allowed us to collect rich data that maximized the range of information to be uncovered.

### **2.6.3 Dependability.**

Dependability was addressed in two ways. First, stepwise replication was utilized by KS and LH during data analysis. KS and LH independently analyzed the data and met periodically to reach a consensus on all codes and themes. These communication sessions were documented by KS. Second, a detailed audit trail documenting the processes of data collection, analysis, and interpretation was made and maintained throughout the study.

### **2.6.4 Confirmability.**

Confirmability of the study was enhanced in three ways, through: 1) triangulation of investigators; 2) memoing; and 3) reflexivity. First, as indicated in our discussion of credibility, triangulation was utilized by involving three investigators and a graduate student throughout the study. Each investigator brought a unique perspective to the project, as well as differing clinical and or/research expertise. Second, detailed analytical memos were kept throughout the data collection, analysis, and manuscript preparation phases of the study. Memoing was guided by Miles, Huberman, and Saldanas [60] perspective on analytic memoing [60]. The majority of memos were focused on challenges as they arose during data collection, code choices, defining codes, emerging patterns and themes, potential connections between themes, and implications and future directions of the study. Third, reflexivity was initiated prior to beginning data collection. KS, who collected and analyzed all data, kept a reflexive journal where potential biases, assumptions, personal values, prior experiences, and expectations were reflexively questioned, reflected on, and documented periodically for the duration of the study.

## Chapter 3: Results

### 3.1 Demographics

A total of 12 interviews were conducted with caregivers in the emergency department at the Stollery Children's Hospital. Demographic variables for all participants and their children are presented in **Table 3-1** and **Table 3-2**, respectively. Our sample is primarily comprised of Caucasian (n=11) mothers (n=9) between the ages of 30 and 41 (n=11) who were married (n=9) and had received a post-secondary education (n=10). The majority of the caregivers in our study reported a household income greater than \$90,000 per annum (n=9).

The children of participants in our study were evenly distributed among three age groups: 3 to 6 years-old (n=4), 7 to 9 years-old (n=4), and 10 to 12 years-old (n=4). The vast majority of children in our study underwent IV insertion procedures (n=11), with only one child having a venipuncture procedure. Most children in our sample had a history of a chronic medical condition (n=10), as described by their caregiver. Children had either visited the emergency department few times (0-4; n=6) or many times ( $\geq 10$ ; n=5), and most had one or greater admissions to hospital (n=8), where one child had multiple long term admissions ( $\geq 45$  days) and two children had prior admissions to the pediatric intensive care unit. Of the children who had IV insertion procedures, most had between 2-5 procedures in their lifetime (n=6). Notably, three children had  $>20$  IV procedures in their lifetime.

**Table 3-1** Caregiver demographic variables

	n(%)
Relation to Child	
Mother	9 (75)
Father	2 (17)
Other	1 (8)

<b>Age</b>	
30-35	5 (42)
36-41	6 (50)
42-57	1 (8)
<b>Marital Status</b>	
Married	9 (75)
Common law	1 (8)
Separated	1 (8)
Single	1 (8)
<b>Highest Level of Education</b>	
High school	2 (17)
Post-secondary	10 (83)
<b>Household Income</b>	
\$15-29,000	1 (8)
\$45-59,000	1 (8)
\$75-90,000	1(8)
Over \$90,000	9 (75)
<b>Ethnicity</b>	
Caucasian	11(92)
Other	1 (8)

**Table 3-2** Child demographic variables

	<b>n(%)</b>
<b>Age</b>	
3-6	4 (33)
7-9	4 (33)
10-12	4 (33)
<b>Procedure</b>	
Intravenous	11 (92)
Venipuncture	1 (8)
<b>Medical History</b>	
Healthy	2 (17)
Chronic illness	10 (66)
<b>Prior ED Visits</b>	
0-4	6 (50)
5-9	1 (8)
≥10	5 (42)
<b>Admissions to Hospital</b>	
0	4 (33)
1	5 (42)
>1	3 (25)



Long Term Admissions (>45 days)	1 (8)
ICU Admissions	2 (17)
<b># of Intravenous Insertions (n=11)</b>	
1 <sup>st</sup> time	2 (18)
2-5	6 (55)
>20	3 (27)
<b># of Venipuncture Procedures (n=1)</b>	
>10	1 (100)

### 3.2 Overall themes

Analysis of the interviews revealed five major themes: 1) source of healthcare information; 2) delivering healthcare information; 3) communicating with caregivers; 4) procedure-related anxiety and long-term effects; and 5) advice from caregivers.

### 3.3 Source of healthcare information

Throughout the interviews, caregivers discussed multiple different sources through which information about IV insertions and/or venipuncture procedures could be provided.

Predominantly, parents appreciated receiving information about the procedure directly from the healthcare provider. Other potential sources of information that were suggested when prompted were: (1) videos; (2) posters; and (3) pamphlets.

#### 3.3.1 Healthcare provider.

Overall, caregivers most valued receiving information about the IV insertion or venipuncture procedures directly from their healthcare provider. Caregivers praised the efforts of their nurses and/or doctors when they explained the procedure to both themselves and their child. Further, they appreciated ongoing dialogue and explanation during the procedure. One mother stated:

“As a parent, [having the procedure described] by the nurse, step by step, is great” [200-003, 8 year-old child, 1 ED visit, 2 IVs].

Another mother highlighted the importance of the doctor explaining the procedure to her child:

“But, um, I did find it quite nice that the doctor was the one that [explained the procedure]. ‘Cause I think sometimes that helps more for kids – that authority...” [200-001, 8 year-old child, 1 ED visit, 1<sup>st</sup> IV].

### **3.3.2 Video.**

Although most caregivers preferred when the IV insertion or venipuncture procedure was explained to them by their nurse or doctor, caregivers commented on the potential merits of sharing information about the procedure through a video. One mother stated:

“I think, maybe for kids, um, that are old enough to comprehend. Um, that a short video might help them kind of know what each step [of the procedure] is going to be... kind of idea. ‘Cause they’re video visual [Chuckling.]” [200-003, 8 year-old child, 1 ED visit, 2 IVs].

Another mother described the benefit of sharing information about the procedure through a video in comparison to receiving information from a healthcare provider:

“I think – I think hearing it from the nurse is fine, if the child feels comfortable with that person. But you don’t really have a way of gauging that. Necessarily, every time, depending on how you know, how much pain they’re in, or why they’re here um... if

they're physically like, really, really sick, um, I think a video would be cool" [200-006, 5 year-old child, 3 ED visits, 4 IVs].

This mother went on to emphasize the utility of a video to both describe the procedure to a child, as well as serve as a tool for distraction:

"[The video] can kind of distract them as they're watching it. Um, and even if they could be watching a video that explains what's going to happen, in a really friendly, easy, kiddy kind of way, you know. And then, even if it could go on a little further ... and then kept it going while [the procedure] was happening... I think that would help. Because they they'd still be distracted" [200-006, 5 year-old child, 3 ED visits, 4 IVs].

### **3.3.3 Poster.**

Having a poster located within patient rooms was discussed as another means for caregivers and their child to receive information about IV insertion and venipuncture procedures. One mother shared the possibility of posters stimulating conversation with their healthcare provider. She stated:

"Um, for an older child this age, probably a poster would work. Um and that way, if you had to have the visual, then you'd think "oh, maybe I should ask about this"" [200-009, 12 year-old child, 100 ED visits, >20 IVs].

However, another mother qualified that posters may inhibit communication between healthcare professionals and caregivers, and more specifically, come across as impersonal and unprofessional:

“As far as a poster on the wall, I think it’s a bit too impersonal, in how it might be presented. ‘Cause the nurse or the doctor would probably be like, “well, the poster on the wall [*chuckling*] explains it perfectly. And then just kind of redirecting it there. I think it would be kind of unprofessional, and uncomfortable” [200-006, 5 year-old child, 3 ED visits, 4 IVs].

### **3.3.4 Pamphlet.**

Caregivers also discussed the potential benefits of receiving pamphlets to share important IV insertion or venipuncture procedure information. One mother emphasized pamphlets as a beneficial source of procedure information because it can be kept and referred to in the future:

“If the – for – for example, if he had a – like a pain and they have some papers, they give it to me to read the information in it, I usually keep for three months. I don’t throw away. I keep that papers in case somebody else get hurt – in the same situations to see how I can manage him, to help with them” [200-012, 3 year-old child, 2 ED visits, 1<sup>st</sup> IV].

Another mother suggested pamphlets as a reasonable tool for sharing procedure information in situations where the procedure needs to be done quickly:

“I think – if it’s something that needs to be done quickly – maybe a quick, simple brochure would be good” [200-006, 5 year-old child, 3 ED visits, 4 IVs].

## **3.4 Delivering healthcare information**

Throughout the interviews, caregivers discussed who should be targeted when sharing information about IV insertion or venipuncture procedures, and how that information should be

shared. Caregivers identified: (1) information should target children; and (2) considerations when delivering information to children.

### **3.4.1 Information should target children.**

Caregivers frequently emphasized the importance of keeping procedure-related information focused on the child, in contrast to speaking with the caregiver. One mother stated:

“For me, I’m used to [the procedure]. I’m used to seeing her get IVs, I’m used to seeing her get needles. I give her needles every day. So for me, it’s okay. I just wanna make sure that she’s calm enough, that she’s not going to – you know, move while they’re doing what they need to do, or you know, that she understands that she’s safe. That it’s okay, no one’s leaving. You know – She’s not alone, so um... And she’s all right with that, as long as she knows that you know, it’s going to be quick. And people are just taking their time with her and explaining steps to her. Then she’s better with it” [200-006, 5 year-old child, 3 ED visits, 4 IVs].

### **3.4.2 Considerations when delivering information to children.**

In addition to directly delivering information about the procedure to the child, caregivers highlighted the importance of their child being actively involved in their care. The following components and/or elements were identified to best involve children in their care: (1) treating children as someone who is going to understand; (2) ensuring children know what to expect; (3) describing the procedure using language and concepts that are familiar to children (i.e., ‘kids terms’); (4) giving children processing time; and (5) involving children in the procedure.

***Treating children as someone who is going to understand:***

The first component in actively involving children in their care involves healthcare providers treating children as someone who is going to understand. One mother elaborated on this concept:

“Today [my daughter] was just very calm, and just everything was explained to her. She was treated like, you know... someone who’s going to understand, instead of just a kid and you know, you’re – you’re being out of control or anxious, and let’s just get this done, so... the patience, the compassion, everything that has been said is really important” [200-006, 5 year-old child, 3 ED visits, 4 IVs].

***Ensuring children know what to expect:***

The second component of children playing an active role in their care is ensuring the child knows what to expect for their procedure. One mother emphasized the importance of her son knowing what is going on. She stated:

“[The nurse was] explaining what she was doing, telling him he was okay if he needed to cover his face, or if he needed to turn away or whatever it was to make him more comfortable and... yeah. So, [the nurse] clearly made sure he understood, ‘cause at eight – he needs to know what’s going on” [200-003, 8 year-old child, 1 ED visit, 2 IVs].

Similarly, another mother stated:

“[My daughter said] “I don’t know what’s going on.” And she’ll say that sometimes. So she likes – she’s at the age where she wants things explained to her. Um... and the more information she has, the better it is. So it’s better for the doctor or the nurse, just to talk directly to her. At this age” [200-009, 12 year-old child, 100 ED visits, >20 IVs].

***Describing the procedure using language and concepts that are familiar to children  
(i.e., ‘kid terms’):***

The third aspect of actively involving children in their care involves describing the procedure to children in a way they understand and can relate to. One mother describes this as using “kid terms”:

“[The nurse] was explaining was she was looking for and describing the veins to him in kid terms” [200-003, 8 year-old child, 1 ED visit, 2 IVs].

Another mother describes how “kid terms” were used when her daughter had an IV insertion:

“[When] they explained the freezing gel and how it’s supposed to make her feel, they compared it to Elsa and how it’s gonna be frozen and... of course, every kid loves Elsa right now, so... Yeah, so that helped too. Um, just relating it to things that kids know...” [200-006, 5 year-old child, 3 ED visits, 4 IVs].

In addition to using kid terms, this mother further emphasized the benefit of using non-threatening language:

“Um, I think in other times, if they could have done things the way they did today, again, explaining to her on her level in a safer – with safer words, like the straw is going in your arm, to – the juice, to make you feel better, you know. Instead of, “okay, we’re just gonna poke you here.” Poke – to an adult, sounds like nothing. To a child, it’s... horrid.

[Laughing.] It’s the worst thing they could ever hear” [200-006, 5 year-old child, 3 ED visits, 4 IVs].

***Giving children processing time:***

The fourth component of actively involving children in their care is giving them adequate processing time to understand and prepare themselves for the procedure. One mother states:

“[My daughter] needs to know. Like – and she needs time to process what’s happening. And then, when she – [the nurses] were more patient with her, to – then – she now she’s – like she watches them put the needle in. Which seems to help her. So today was good” [200-004, 10 year-old child, 10 ED visits, 4 IVs].

***Involving children in the procedure:***

The fifth component in actively involving children in their care includes healthcare providers involving children in the procedure, e.g., by giving them choices or opportunities for decision-making or input where possible. The caregivers in this study shared a number of different strategies to empower children to have a role in their procedure. One mother shared her daughter’s role in the procedure as she was actively engaged in her IV insertion:

“[The procedure today went well because] they were patient, for one thing. [*Chuckling*]. Um, [*chuckling*] and [the nurse] was just very calm in asking [my daughter] like how she wanted [the IV procedure] done. So it was more so letting her know that you know, this isn’t being done to you. That you’re still you know, a part of this. And just letting her know like... okay, do you want the board underneath your arm? Or you know, “does it still hurt?” And just kind of letting her know that – what’s gonna happen next. You know what I mean? Like, yeah. So I think... just this – strategically telling her about it. And just calmly doing it, in a manner that’s not gonna scare her. [200-006, 5 year-old child, 3 ED visits, 4 IVs].



### 3.5 Communication with caregivers

Caregivers emphasized the importance of communication with their healthcare providers regarding IV insertion and venipuncture procedures throughout the interviews. Two main themes emerged: (1) Caregivers want to be supported by their healthcare providers; and (2) there are specific areas where caregivers feel that more information needs to be provided from healthcare providers.

#### 3.5.1 Supporting caregivers.

Two main ways of supporting caregivers emerged throughout the interviews: (1) empowering caregivers to communicate; and (2) reassurance.

##### *Empowering caregivers to communicate:*

Caregivers highlighted the potential for various sources of healthcare information, like posters and pamphlets, to facilitate communication with their healthcare providers. One mother discussed the potential of posters to spark conversation:

“I think the poster would be good at this point in time for my age kids. I really do. It’s visual. Um, yeah. That way it would just spark conversation, I guess. It would be good”  
[200-009, 12 year-old child, 100 ED visits, >20 IVs].

One father suggested the potential for a video to inspire questions that he can then later bring up when his child’s physician is explaining the procedure in detail. He states:

“And then, if you – when you sit down with your anesthesiologist, and he’s gonna explain the IV. Then, if you have questions there, you could say, okay, when he’s doing

this, what – you know, I read – I saw this little video. Is this okay if I do this, if they have any questions” [200-010, 7 year-old child, 2 ED visits, 3 IVs].

***Reassurance:***

The need for reassurance was also brought up by one father as a meaningful way to support caregivers through their child’s procedure. He stated:

“[During the procedure] have the doctor say, “No, you’re doing good, dad. Just keep talking to [your son], keep talking to him.” So maybe, if that’s explained ahead of time, that you should do what naturally comes to you, like for distraction just talking to him, have him look at you in the eyes. Ah, that – feel free to do that. And if there’s something that... um, you know that you shouldn’t be doing, or that may obstruct the medical procedure, [the doctor] will let you know. But otherwise, continue what you’re doing until you’re told otherwise” [200-010, 7 year-old child, 2 ED visits, 3 IVs].

**3.5.2 Specific areas where more information needs to be provided.**

Three main areas were identified by caregivers as needing to be better addressed by their healthcare providers. These areas include: (1) basic information about Maxilene; (2) nature and duration of pain or discomfort; and (3) what happens after the IV is inserted.

***Basic information about Maxilene:***

Maxilene, a fast-acting topical anesthetic, was offered to all children in this sample. Of the children offered Maxilene, all but one accepted and underwent their procedure after the topical anesthetic was applied. Although caregivers nearly unanimously agreed that Maxilene was helpful for their child during the procedure and that they would request it again for future

procedures, some caregivers felt they or their child lacked basic information about the cream (e.g., what it is, how it works, how long it lasts). One father thought more information about Maxilene would have been beneficial to him:

“I’m not sure too much about the information about the cream. So maybe... information about that would help me out. Yeah. ‘Cause they – they don’t normally give it to [my son] at the bloodwork clinic” [200-002, 6 year-old child, >20 ED visits, >20 venipunctures].

Similarly, another mother felt her daughter would have benefitted from receiving information about Maxilene. She stated:

“The only thing that wasn’t explained [to my daughter] was the numbing cream. That was the only thing that was left out. And more information about that – more information about that – would have been really good [for her]” [200-009, 12 year-old, 100 ED visits, >20 IVs].

***Nature and duration of pain/discomfort:***

One caregiver thought more information about pain could have been provided to her daughter before the procedure. She states:

“Is it gonna hurt right now? What’s it gonna hurt? How long is it gonna hurt for? Ah, would be good to know beforehand” [200-009, 12 year-old child, 100 ED visits, >20 IVs].

***What happens after the IV is inserted?:***

While caregivers in our sample felt that the immediate procedure itself was generally well described, one caregiver thought their child could have received more information about potential discomfort after their IV had been inserted. She stated:

“I think, more for the child to be told... that not only will there be an initial pinch – but it will probably be uncomfortable... for the duration that it’s in. Um, so that they don’t think once the pinch is done, it’s all done. But rather, that you know, if someone pulls on it or you turn the wrong way, there’s still going to be that discomfort that happens” [200-003, 8 year-old child, 1 ED visit, 2 IVs].

### **3.6 Procedure-related anxiety and long-term effects**

Throughout the interviews caregivers shared experiences, including aspects of the procedure or context in which the procedure was done, that caused anxiety for the child and/or the caregiver, and in some cases resulted in long-term negative effects for the children. Several factors emerged within this theme: 1) traumatic experiences; 2) procedures in young children; 3) procedures at non-pediatric centres; and 4) caregiver and child anxiety.

#### **3.6.1 Traumatic experiences.**

Caregivers shared many stories of their child’s prior experiences when having IV insertion and/or venipuncture procedures; from their perspective, some of these previous experiences had been traumatic for their children. Although each experience was unique, caregivers consistently reported enduring negative effects of their child’s experiences. One mother reflected on her daughter’s fear of having an IV insertion:

“She was crying [today during the procedure]. Just the fear, again. Because she’s done this so many times and she knows um... And I think, really, the first time that she ever experienced it, when she was originally diagnosed with Type 1, they had to use her feet – so they – they were poking her feet, they were poking her arms, they were poking her fingers, they were poking every inch of her. And that stays with her. She’s... the kind of kid where, something happens, it’s almost traumatic to her. And – and she never forgets” [200-006, 5 year-old child, 3 ED visits, 4 IVs].

### **3.6.2 Procedures in young children.**

Procedures in young children were consistently reported as the most challenging and the most stressful procedures for caregivers. One father shared:

“At the beginning it was real tough. To hold [my son], and he’d kinda fight ya – and it almost felt like you’re – you were gonna break him, almost” [200-002, 6 year-old child, >20 ED visits, >20 venipunctures].

Similarly, another mother shared being nervous when her child was young, but feeling more confident when her son needs a procedure now because she knows he is going to be okay. She stated:

“Now it’s okay. ‘Cause I know that [my son] is going to be okay. When he was younger, we’d be a bit nervous, ‘cause you never know how they’re going to react [to the procedure]. Um... but now it’s... it’s fine” [200-008, 10 year-old child, >20 ED visits, >20 IVs].

Another father shared in detail a negative experience he had when his son needed a venipuncture as an infant:

“He had a really bad experience when he was a baby. He was actually getting blood work. I think he was maybe oh – he was probably six to eight months. We were at a [urban bloodwork clinic], and the phlebotomist has missed his vein. ‘Cause she went in at first – she doesn’t even remember – she had him all rigged up and then she’s like, “oh, I’m not even ready yet.” Yeah. She was giving him the needle, but didn’t have the proper tubes that she needed. She was missing one. And ah – so it was really painful – he was really crying. Because they didn’t do anything like the magic cream or anything like that. And being he’s so tiny with the tiny, butterfly needle or whatever it was, she was having a lot of issues and... and ah, was missing the vein. I think she had to do it twice. Um – and so that was – I mean, that was just tough for us, because he was so little, and to see that there was – you know, not the proper um... like she wasn’t prepared and... and ah... she didn’t feel very happy about it. Like she felt bad as well – but it was just having to do it again. And we really wanted to get the – you know, these tests done. And he really had no problem going to see his pediatrician up to that point. And after that – he just heard doctor. And it was just like – even at that age, it was just like... he was scared. ‘Cause I think he thought every time going to the doctor was going to be like that” [200-010, 7 year-old child, 2 ED visits, 3 IVs].

### **3.6.3 Procedures at non-pediatric centres.**

Caregivers consistently reported strongly preferring to have their child's procedures done in a specialized pediatric centre. One mother emphasized that rural centres are not used to working on kids. She stated:

“Um, in [rural town] this morning, like they flat-out said that they're not used to working on kids. So – ‘cause they tried to put an IV in him there and they couldn't get it in. So... um, it's just different here. Like the people here at the Stollery work with kids, so it's – just a little more comforting knowing that, too. That... they're used to working with the little veins...” [200-005, 4 year-old child, 2 ED visits, 2 IVs].

This mother further specified:

“Ah people, I think [at the Stollery Children's Hospital] people are... people are more aware of how to treat a child. Whereas outside, sometimes... they're not as... caring...” [200-005, 4 year-old child, 2 ED visits, 2 IVs].

Another mother drew on her experiences at an urban venipuncture clinic:

“Yeah. They're more... harsh at [urban venipuncture clinic]. They don't really explain what they're doing. They just sit you down and... take blood out of you and away you go.” [200-009, 12 year-old child, 100 ED visits, >20 IVs]

### **3.6.4 Caregiver and child anxiety.**

Caregivers also shared concerns about their own anxiety, as well as their child's anxiety. Caregivers concerns were focused primarily on two factors: (1) caregiver concern about procedure-related complications; and (2) their child's anticipation of the procedure.

#### ***Caregiver concern about procedure-related complications:***

Caregivers often reported anxiety about complications arising from their child's IV insertion or venipuncture procedure. One mother stated:

“Well, there's always so many like – I don't know, I always like worry if he jerks the wrong way, if – they're gonna like cut him, or something. I don't exactly know what they do even, so...” [200-005, 4 year-old child, 2 ED visits, 2 IVs].

Caregivers also often reported concern about their child having to have multiple needles because of challenges inserting the IV line:

“I was concerned if she was actually gonna hold still, and if she was gonna have to get poked again and... but she was okay. Surprised me” [200-007, 10 year-old child, 5 ED visits, 3 IVs].

Similarly another mother stated:

“... Before, I kind of just like – think like, “oh my God, I just hope they get it [*chuckling*] the first time and it's not... too bad. ‘Cause that's when it starts to hurt worse, is when they have to do it over and over...” [200-005, 4 year-old child, 2 ED visits, 2 IVs].

### ***Child anticipation of the procedure:***

Caregivers also shared concern about their child's anticipation of the procedure. Specifically, caregivers reported their child's anxiety to be the worst before the procedure. One mother stated:

“So... I think it was more the before the IV part that was a problem. Because he was anxious about the idea of getting one. Um, more than the actual reality of one” [200-003, 8 year-old child, 1 ED visit, 2 IVs].



### **3.7 Caregiver advice**

Throughout the interviews, caregivers reflected on what worked well for them on the day of the procedure, as well as for past procedures, and provided advice for other caregivers in similar situations with their child. Caregivers emphasized parents need to: (1) stay calm; (2) communicate with the healthcare providers and ask questions; (3) be straightforward with their child; (4) do what works for their child; and (5) know that it will get easier.

#### **3.7.1 Stay calm.**

Staying calm was the most frequent and heavily emphasized advice offered by caregivers of children who have had an IV insertion or venipuncture procedure. One mother suggested:

“Don’t make a big deal out of [the procedure] with your kids, ‘cause the bigger – you know, production you put on for them, the more upset they become, so...” [200-001, 8 year-old child, 1 ED visit, 1<sup>st</sup> IV].

Another mother highlighted the challenges associated with remaining calm, and suggested that sometimes caregivers need support. She states:

“So, like sometimes, maybe the parents might need more support than the kid. ‘Cause [my daughter] was like, okay, and I was like in tears” [200-004, 12 year-old child, 10 ED visits, 4 IVs].

#### **3.7.2 Communicate and ask questions.**

Caregivers also highlighted the importance of taking the initiative to communicate with their healthcare provider and ask questions. One father highlighted the importance of

communicating with his healthcare provider so he can better understand his role in the procedure. He stated:

“If you’re not sure, ask. Yeah. And I would even – just as – and even if you’re not sure, but... whoever’s doing the IV or whatever, just ask them how is it gonna be done, and how can I help. Is there a way that I can help you make your job easier while you’re doing that? And maybe, distract my child or me taking a position on my child – do you actually have that communication between the two of you... as opposed to waiting for that individual to try and tell you what to do. ‘Cause again, it’s routine for them. But if things start to go a little bit sideways, or not as planned, then you’ve already discussed that. And you already kinda have that relationship too, that you know there’s a believable communication here” [200-010, 7 year-old child, 2 ED visits, 3 IVs].

### **3.7.3 Be straightforward with your child.**

Caregivers often emphasized the importance of honestly communicating with their child about the procedure. One mother highlighted being honest about the pain, and stated:

“Um... I would say just be straightforward with [your child]. Because it’s gonna... pinch. [Chuckling]. You know... it’s – it [stammers] and I guess don’t gloss over it. Because they’ll just be mad at you after. [Laughing]” [200-003, 8 year-old child, 1 ED visit, 2 IVs].

### **3.7.4 Do what works for your child.**

Doing what works for your child was frequently suggested by caregivers; further, children in the sample reacted differently (e.g., one child did not want Maxilene while most did;

some children did not want to watch the procedure while others did). Ultimately, caregivers emphasized that no one knows a child better than their parent, and that parents should use that knowledge to best comfort their child when they need it most – during a procedure. One mother’s suggestion was:

“Um... yeah, just that... the child may need their own way to [cope]. Like I said before, [my daughter], she wants to watch [the procedure]. So maybe like, try all the usual – like, “don’t look at your arm” or “hold my hand” and “look away.” But it might not work for all kids. So it’s kind of – you have to – think if your child wants to watch, you should let them watch” [200-004, 12 year-old child, 10 ED visits, 4 IVs].

Similarly, another father emphasized the instinctual component to meeting his child’s needs before and during the procedure. He stated:

“You just kinda go into instinct for your child” [200-010, 7 year-old child, 2 ED visits, 3 IVs].

### **3.7.5 It gets easier.**

Finally, caregivers advised that although procedures are challenging for both caregiver and child in the beginning, in time, it does get better. One father stated:

“It – at first it’s rough [when your child needs a procedure] but – in time, it gets a little – a lot easier” [200-002, 6 year-old child, >20 ED visits, >20 venipunctures].

## **Chapter 4: Discussion**

It has been well established that poorly managed procedural pain in children can have a negative, and sometimes life-long, impact. Despite this, the published literature points to a substantial knowledge to practice gap in the management of procedural pain from IV insertion and venipuncture procedures in pediatric EDs. The present study demonstrates that while many positive steps are being taken to manage children's pain and provide both children and their caregivers with information prior to and during IV insertion or venipuncture procedures in the ED, greater efforts are needed to empower children and their caregivers to have a more active role in their healthcare, in all clinical settings. There are likely differences in the management of procedural pain in children across different types of sites (e.g., general EDs, non-pediatric phlebotomy labs), thus, more active steps are needed to address barriers faced in these clinical settings.

### **4.1 The influence of local policy**

The Stollery Children's Hospital pediatric ED is an example of a department actively working to implement evidence-based strategies for pharmacological management of pediatric procedural pain. Considerable efforts are being made to ensure all children have the option of having a topical anesthetic applied prior to having a painful needle procedure, such as IV insertions and venipuncture. All patient rooms have a poster encouraging caregivers to ask their healthcare provider about the use of a topical anesthetic prior to their child having a painful needle procedure. Throughout the interviews, it became apparent that caregivers were aware of the availability of Maxilene, and each child was offered it prior to their procedure. All caregivers of children who utilized Maxilene prior to their procedure were pleased that their child was given

the option of having the anesthetic applied, thought it helped their child, and would request it again for future procedures. Nurse-initiated protocols exist within the department for a number of pain management strategies including: acetaminophen, ibuprofen, and Maxilene application. In a survey of Canadian pediatric emergency physicians, pain-specific nurse-initiated protocols were reportedly used in only 62% of EDs, and of the nurse-initiated protocols, 40% were for acetaminophen, 27% were for ibuprofen, and only 5% were for the application of a topical anesthetic [3]. The Stollery Children's Hospital ED is one of few pediatric EDs in Canada that have pain-specific nurse-initiated protocols in place. Empowering nurses to provide these pharmacological pain management techniques without the delay associated with consulting a physician not only reduces the pain children experience, but also decreases the time to analgesia and increases the number of children who receive analgesia in the ED [75]. Pain-specific nurse-initiated protocols also facilitate physician/nurse collegiality, foster nurse autonomy, and play a significant role in shaping ED culture [76]. Having a Maxilene nurse-initiated protocol in the Stollery Children's Hospital ED very likely impacted the experience of caregivers and children included in this study.

#### **4.2 The importance of communication and involvement in healthcare**

All of the caregivers in this study described being pleased with the care their child had received in the Stollery Children's Hospital ED. Throughout the interviews, caregivers emphasized the value of receiving information about the IV insertion or venipuncture procedure directly from their healthcare provider in contrast to other methods of sharing information (e.g., videos, pamphlets, posters). The majority of caregivers described feeling well informed about their child's procedure, however, caregivers expressed that the issue of greatest importance was that their child felt well prepared and supported throughout their procedure. Caregivers described

the following methods to share information about the procedure with children: treating children as someone who is going to understand, ensuring children know what to expect, describing the procedure using language and concepts that are familiar to children, giving children processing time, and involving children in the procedure (e.g., allowing them to make decisions or choices where possible). Caregivers expressed appreciation for the patience and kindness healthcare providers showed their children as they went through the procedure step-by-step, particularly during periods of anxiety and distress before and during the procedure.

The experiences shared by the caregivers in our sample support the findings of previously published research that indicate providing analgesia alone does not predict patient and caregiver satisfaction with ED care [77]. Patient and caregiver satisfaction with care in the pediatric ED is complex and multifactorial [77]. However, it has been well established in pediatric and adult patient populations that effective communication between patients, caregivers, and their healthcare provider leads to greater self-reported patient and caregiver satisfaction [77, 78]. Effective communication strategies, such as showing kindness and patience, speaking directly with a child, incorporating the child's knowledge and preferences into a procedure, and providing developmentally appropriate information and education using language that is familiar to the child, are essential to providing family-centred pediatric emergency care [79]. Dudley, et al. [80] describes patient and family centred care as, "an approach to the planning, delivery, and evaluation of healthcare that is grounded in a mutually beneficial partnership among patients, families, and healthcare professionals" (p.e255). Caregivers and patients who feel heard, are involved in making decisions about their care, and receive appropriate information report less anxiety and interpret their experience more positively when being cared for in the pediatric ED context [79]. Given the importance of communication and patient- and family-centred care in

pediatric and adult populations, the methods for communicating healthcare information described by caregivers in our sample, while intended for children in the ED, would have utility across all healthcare settings [81-83].

### **4.3 Delivering healthcare information**

Throughout the interviews, caregivers emphasized the importance of communication with their healthcare providers. Caregivers want healthcare providers to be their primary source of information about IV insertion and venipuncture procedures. However, caregivers did consider other methods (e.g., videos, posters, pamphlets) as useful secondary sources of information. Caregivers described videos, posters, and pamphlets as potential methods for sharing information that could improve caregiver and child communication with healthcare providers. By providing caregivers and children with information about procedures, the caregivers in our sample described potential opportunities for education, stimulating conversation about the procedure, and giving caregivers the information they need to ask informed questions to their healthcare providers.

Ongoing Canadian studies like Be Sweet to Babies [84], the Commitment to Comfort Program [85], and It Doesn't Have to Hurt [86] are investigating the impact of KT tools targeting caregivers, specifically videos, posters, and social media, on the management of pain across various healthcare settings, and for different populations and indications. Be Sweet to Babies has developed a YouTube video targeting caregivers of infants, designed to share information about evidence-based strategies to manage needle-related procedural pain [84]. It Doesn't Have to Hurt similarly developed a YouTube video targeting caregivers of young children, designed to share information about evidence-based strategies to manage vaccine-related procedural pain. The It

Doesn't Have to Hurt project is also utilizing various forms of social media to disseminate evidence to caregivers in partnership with an online parenting magazine, YummyMummyClub.ca [86]. Finally, the Commitment to Comfort Program, to our knowledge, is the only study looking specifically at pain in the pediatric ED context. The Commitment to Comfort Program is a quality improvement initiative at the Alberta Children's Hospital (Calgary, Alberta) targeting pain management for limb injuries. In a retrospective assessment of pain care processes and outcomes for children with limb injuries, it was found that only 18% of children were asked to rate their pain at triage, and of children who rated their pain as moderate or severe, only 49% received analgesia during their ED visit (Personal communication, Dr. Jennifer Thull-Freedman, Medical lead for Quality Improvement and Safety, Alberta Children's Hospital). In response to these findings, the program developed and tested two KT tools: (1) posters; and (2) a "comfort menu." These KT tools informed caregivers of a variety of different options available to make their child feel more comfortable when they were in pain or needed a painful procedure, like IV insertions or venipuncture. Implementing the KT tools in their ED resulted in decreased time between the child first reporting pain and receiving analgesia, and more children and caregivers self-reporting satisfaction with the pain management received (Personal communication, Dr. Jennifer Thull-Freedman). Their team felt that caregivers were empowered to request analgesia when they otherwise might not have been aware (a) what the analgesics were; and/or (b) that the ED had them readily available and healthcare providers were willing to immediately provide children with what they or their caregiver request (Personal communication, Dr. Jennifer Thull-Freedman). This study was thought to shift the ED culture to prioritize pain. Empowering caregivers to request evidence-based pharmacological and non-pharmacological pain management for their child was integral in facilitating a "comfort care"



culture, in part because it may have held healthcare providers actively accountable for the treatment of children's pain (Personal communication, Dr. Jennifer Thull-Freedman).

Using KT tools to empower patients and/or caregivers to play a more active role in their care has been shown to improve health outcomes. In a study aiming to encourage older patients and their caregivers to have an active role during a care transition, a KT tool was developed and implemented to build capacity around the following content areas: medication self-management, a patient-centered record, primary care and specialist follow-up, knowledge of warning symptoms or signs of worsening health condition [87]. Older patients and their caregivers who received the intervention had greater confidence in their ability to manage their health condition, communicating with healthcare providers, and understanding their treatment plan, and overall, were found to have a more active role during care transitions [87]. Similarly, in a KT effort to prevent falls in a hospital in-patient ward, nurses were educated about fall prevention strategies. After the intervention, nurses had increased knowledge and use of fall prevention strategies increased in frequency [88].

#### **4.4 Procedure-related anxiety and long-term effects**

IV insertions and venipuncture are the two most common procedures in the ED setting, however, previous research that indicates what may be considered 'simple' or 'routine' procedures by healthcare providers can create anxiety and, in some cases, long-term negative effects (e.g., fear of healthcare providers) for caregivers and their children [18, 19]. Caregivers in our sample frequently described anxiety around procedure-related complications (e.g., their child being cut) and their child experiencing greater pain from multiple needle pokes due to unsuccessful procedures. Effectively utilizing analgesia for procedures like IV insertions and

venipuncture can not only substantially improve the pain children experience, it can also improve the success rate of procedures and shorten the overall procedure time, highlighting, again, the importance of effective knowledge translation in this area [89].

Numerous caregivers shared distressing experiences about procedures carried out at non-pediatric urban and rural centres. Caregivers described feeling that healthcare providers in these settings were lacking preparedness, had little confidence in, or knowledge about conducting IV insertion and venipuncture procedures in children. In a recent survey of pediatric pain management practice and policies in Alberta general (n=70) and pediatric (n=2) EDs, it was noted that policies around pediatric pain are severely lacking. Less than one third of EDs reported having a policy for mandatory pain documentation, and only one quarter had a policy mandating the use of a topical anesthetic prior to IV insertions and venipuncture procedures [30]. Documentation of pain management interventions in patient charts is often inconsistent, and is rarely inclusive of non-pharmacological interventions [90]. Implementing pain-related policies has been linked with an increase in the number of patients receiving analgesia for procedures in the ED setting [91]. Additionally, physician administrators from general ED settings continue to cite lack of education in pediatric analgesia as the most significant barrier to providing optimal pain management and care [30]. Given 85% of Canadian children in need of emergency care are seen in non-pediatric EDs, our study further supports the urgent need for knowledge translation efforts targeting the general ED setting [92, 93].

#### **4.5 Summary**

KT tools targeting caregivers are an important and potentially effective way of sharing research evidence in a way that is accessible and catalyzes change in practice. Caregivers in our

study report that poorly managed procedural pain continues to persist in emergency care settings, and we know from previously published research that this may cause long term negative effects for both caregivers and children. Caregivers want to better understand how they can reduce their child's pain, and they want to work together with their healthcare providers to make it realize. Empowering caregivers to ask informed questions and request evidence-based pharmacological and non-pharmacological treatments is an important next step in closing the knowledge to practice gap in pediatric procedural pain management. Potential next steps based on this research may include developing a KT tool that aims to raise awareness about pharmacological and non-pharmacological pain management strategies that are available in the ED, and how caregivers can ask for their child to receive those treatments. Because educational posters have been successfully utilized to educate caregivers about the availability and use of Maxilene for procedural pain in the Stollery Children's Hospital ED, utilizing this format to provide information to caregivers about procedural pain management may be appropriate in this specific environment. However, given the vast majority of children requiring emergency care are treated in general EDs, KT efforts extending beyond tertiary care pediatric centres are required.

#### **4.6 Strengths and limitations**

This study makes an important contribution to the existing published literature. Our sample provides in depth descriptions of caregiver experiences and information needs when their child is undergoing a painful procedure in a pediatric ED. The majority of caregivers in our sample had been through the experience of having a child require a painful procedure on multiple occasions, and in multiple healthcare settings (e.g., pediatric ED, urban and/or rural general ED, phlebotomy lab). Because of their child's experience with multiple painful procedures, caregivers were able to carefully reflect on the management of procedural pain

across a variety of ages and stages, as well as how their information needs have or have not evolved. Finally, our study was strengthened by the guidance of Guba's [74] naturalistic mode for dealing with questions of trustworthiness, and bolstered our methodological rigor.

This study is limited by a number of factors. Our sample is limited to primarily Caucasian, married females, who have a post-secondary education and report a household income greater than \$90,000 per annum. Children of ethnic minority groups, particularly those of black and Hispanic descent, are known to rate and interpret their pain differently than Caucasian children [8]. Further research is needed to understand the experiences and information needs with consideration of broader ethnic diversity. Similarly, caregivers with less formal education and/or lower income may have different experiences and information needs when their child is having a painful procedure. Our sample also primarily includes children who have chronic illnesses; only two children in our study were described as being healthy with no medical history by their caregivers. As a result, the majority of children in our study had previous experience with painful procedures. There were only two children included who had their first IV insertion or venipuncture procedure on the day of interview. Caregivers of children who are having first time IV insertion or venipuncture procedures may have different experiences and information needs than more experienced caregivers of children who have had multiple painful procedures in the past. Additionally, because this study was conducted in an urban specialized pediatric centre, the results may not represent the experiences of caregivers and children undergoing painful procedures in other environments (e.g., non-pediatric centres). Finally, our study is limited by caregivers' previous experiences and knowledge regarding painful procedures and the minimizing of associated pain; if they were unaware of available pain treatment

modalities that *could* have been offered to them, they would not be in a position to report dissatisfaction with *not* receiving them.

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## Tables

**Table 3-1** Caregiver demographic variables

	<b>n(%)</b>
<b>Relation to Child</b>	
Mother	9 (75)
Father	2 (17)
Other	1 (8)
<b>Age</b>	
30-35	5 (42)
36-41	6 (50)
42-57	1 (8)
<b>Marital Status</b>	
Married	9 (75)
Common law	1 (8)
Separated	1 (8)
Single	1 (8)
<b>Highest Level of Education</b>	
High school	2 (17)
Post-secondary	10 (83)
<b>Household Income</b>	
\$15-29,000	1 (8)
\$45-59,000	1 (8)
\$75-90,000	1(8)
Over \$90,000	9 (75)
<b>Ethnicity</b>	
Caucasian	11(92)
Other	1 (8)



**Table 3-2** Child demographic variables

	<b>n(%)</b>
<b>Age</b>	
3-6	4 (33)
7-9	4 (33)
10-12	4 (33)
<b>Procedure</b>	
Intravenous	11 (92)
Venipuncture	1 (8)
<b>Medical History</b>	
Healthy	2 (17)
Chronic illness	10 (66)
<b>Prior ED Visits</b>	
0-4	6 (50)
5-9	1 (8)
≥10	5 (42)
<b>Admissions to Hospital</b>	
0	4 (33)
1	5 (42)
>1	3 (25)
Long Term Admissions (>45 days)	1 (8)
ICU Admissions	2 (17)
<b># of Intravenous Insertions (n=11)</b>	
1 <sup>st</sup> time	2 (18)
2-5	6 (55)
>20	3 (27)
<b># of Venipuncture Procedures (n=1)</b>	
>10	1 (100)

## **Appendix A: Letter of Initial Contact**

### **PARTICIPANT CONSENT FORM**

**Title of Project:** Procedural pain in children: A qualitative study of caregiver experiences and information needs

**Principal Investigator:** Dr. Lisa Hartling  
Tel: 780.492.6124  
Email: hartling@ualberta.ca

**Research/Study Coordinator:** Kassi Shave  
Tel: 780.492.5074  
Email: kshave@ualberta.ca

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#### **Why am I being asked to take part in this research study?**

You are being asked to participate in this research study because your child requires an intravenous (IV) line and/or bloodwork. This study will help us understand caregiver experiences around their child's painful medical procedures, as well as the information caregivers need to help manage their child's pain and distress during medical procedures.

This handout is one part of giving informed consent. Before you make a decision about participating in this research study, one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form to keep for your records. Please take the time to read this carefully.

#### **What is the reason for doing the study?**

We are trying to find ways to help parents better manage their child's pain and distress from medical procedures. To do this, we need to listen to caregiver's experiences after their child has had a painful medical procedure. We also need to learn more about the information caregivers would have liked to receive to better manage their child's pain and distress during medical procedures.

#### **What will I be asked to do?**

If you choose to participate in this study, a researcher will ask you to share your experience around your child having an intravenous (IV) line and/or bloodwork procedure. We will ask some questions about:

- a) Your child and his/her previous medical history;
- b) How you managed your child's pain during their medical procedure;
- c) What health care professionals did to manage your child's pain during their medical procedure;
- d) Information you need so you can better help your child through their medical procedure.

This should take approximately 20-30 minutes of your time, and can be done at either your child's bedside in the emergency department or in a private room. If your child's healthcare team comes during the interview, the interview will be paused and continued when they leave. These interviews will be audio recorded so the researchers can refer to your responses again after the interview. You can request that the audio recording be shut off at any time. The care your child

receives in the emergency department will not change in any way if you do or do not participate in this research study.

**What are the risks and discomforts?**

We anticipate you will be at no risk for harm or discomfort during this study. It is your choice to participate, and you do not have to answer any questions you do not want to.

**What are the benefits to me?**

You are not expected to gain any benefit from being in this research study. However, you will be helping us understand the best way to involve parents in managing their child's pain and distress from medical procedures.

**Do I have to take part in the study?**

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the care that your child is entitled to. Throughout the interview, you do not have to answer any questions that you are not comfortable with. You can withdraw from the study at any point up until the interview is finished. If you withdraw, the researcher will ask if your responses up until the point of withdrawal can be used for the study. This is your choice, and your response will in no way affect the care your child receives in the emergency department.

**Will I be paid to be in the research study?**

You will receive a \$10.00 Tim Horton's gift card as a token of appreciation for participating in the research study. If you choose to withdraw from the study before the end of your interview, you will still receive the gift card.

**Will my information be kept private?**

During the study we will be collecting data about you. We will ensure that this data is kept private. No data relating to this study that includes you or your child's name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private. After the study is done we will continue to securely store the data collected from your interviews. As per University of Alberta regulations, we will keep the audio recordings of your interviews for a minimum of five years. These will also be securely stored and not used for any other purposes.

**What if I have questions?**

If you have any questions about the research now or later, please contact Ms. Kassi Shave (780-492-5074) or Dr. Lisa Hartling (780-492-6124). If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at (780) 492-2615. This office has no affiliation with the study investigators.

This research is being partially supported by the Women's and Children's Health Research Institute (WCHRI). You are entitled to request any details concerning this compensation from the Principal Investigator.

**Appendix B: Demographic Question Guide**

1. What is your age?
2. What is your marital status?
3. What is your occupation?
4. What is the highest level of education you have achieved?
5. What is your household income per year? (<\$15,000; \$15-29,000; \$30-44,000; \$45-59,000; \$60-74,000; \$75-90,000, over \$90,000)
6. Do you identify with an ethnic minority group? (First Nations, Chinese, South Asian, Black, Filipino, Latin American, Southeast Asian, Arab, West Asian, Korean, Japanese, Other)
7. What is your child's first name?
8. What is your child's age?
9. Does your child have any pre-existing medical conditions? If yes, please specify.
10. Has your child previously been to the emergency department? If yes, how many times?
11. Has your child ever had a previous serious illness for which they needed medical care, an emergency department visit, or admission to the hospital? If yes, please specify.
12. Approximately how many times has your child had an intravenous insertion and/or bloodwork?

## **Appendix C: Interview Guide**

### **Procedure**

1. Tell me about your experiences when your child had the bloodwork/intravenous insertion today.
2. What was it like for you as a parent when your child had the procedure?
3. What strategies were put in place by health care professionals to help your child? (For example, did they use drugs? Information? Other approaches?)
  - a. Did anyone mention other strategies like distraction (music, video, singing, etc)?
4. Did you do anything to manage your child's pain during the procedure?
  - a. Did you talk with your child, holding your child, use a smart phone/iPad (games etc.) as distraction?
  - b. Did you use an incentive with your child, like offering to give your child a toy or a treat when the procedure is done?
5. How did your child cope with the procedure?
  - a. Is this the same or different than they have reacted in the past?
  - b. Is there anything you have done to make them more comfortable with procedures?
6. What were your child's emotions like before/during/after the procedure?
7. What were your emotions like before/during/after the procedure?
  - a. Were you concerned about your child's reaction?
  - b. Were you worried about what was going to happen before/during/after the procedure?
  - c. Thinking back to previous procedures, even when your child was very young, how have these emotions/thoughts changed? What might have resulted in these changes?
8. Has your child ever had a painful procedure (like bloodwork, IV, stitches) done outside of the Stollery?
  - a. How would your experience there compare to here?

### **Information**

9. How well was the procedure explained to you prior to your child having bloodwork/IV insertion?

- a. Did what was explained to you prior to the procedure prepare you for how things actually went?
  - b. Did you learn anything about managing your child's pain based on the information provided to you before/during/after the procedure?
  - c. Is there anything that could have prepared you better?
- 10. What information would you have liked to receive so you could help your child through the procedure today?
- 11. How would you have liked to receive this information (e-book, whiteboard animation videos, infographics, healthcare provider, etc.?)
- 12. How would you seek health care information if you were at home, your child was sick, and you didn't have easy access to a health care provider?
- 13. What makes you trust health care information?
- 14. If there were new effective ways to manage your child's pain that you didn't know about, and your health care provider didn't immediately explain to you, how would you like to receive information about these pain management strategies?
  - a. Would you prefer a brochure? A poster in your room? A storybook for you and your child to read? A video on an iPad or the TV? Something else?

### **Other**

- 15. Do you have any advice for parents of children having bloodwork/intravenous insertion?
- 16. Are there things you would do differently if your child needs bloodwork or intravenous insertion in the future?
- 17. Do you have any stories you would like to share with me?
  - a. Other painful procedures in child's life?
  - b. Any other circumstance where you needed health information?